TRAUMATIC BRAIN INJURY TRAINING FOR COMPENSATED CAREGIVERS: EXPERIENCES IN NORTH CAROLINA

by

Emily Nicole Fender

Honors Thesis

Appalachian State University

Submitted to The Honors College
in partial fulfillment of the requirements for the degree of

Bachelor of Science

May, 2017

Approved by:

Louise Keegan, Ph.D., CCC-SLP, Thesis Director

Cheryl Fox, M.A., C.A.S., Second Reader

Ted Zerucha, Ph.D., Interim Director, The Honors College

Abstract

Purpose

Individuals with traumatic brain injury (TBI) often experience cognitive deficits that result in difficulties with language and social skills. While direct Speech and Language Therapy can help with these difficulties, there is increasing support for implementing other intervention methods (e.g. environment modification and communication partner training). Training communication partners of individuals with TBI has proven to be an extremely effective means of intervention for this population, however there has been limited research that has specifically examined paid caregivers and the training they receive as communication partners. This study aimed to evaluate the current state of communication training among professional caregivers in North Carolina.

Method

A total of 13 caregiver participants completed an online anonymous survey that gathered information regarding their demographics, completed training programs, understanding of communication difficulties associated with TBI as well as useful strategies for communication, common conversational contexts, confidence in communicating, and desire for additional training. Their responses were qualitatively analyzed.

Conclusions

It was found that the majority of the caregivers were female and had some form of higher education. Most had been employed with individuals with TBI for 5 years or less and only currently served one or two individuals with TBI. They worked in a variety of settings and their job titles could be described as either “Administrative Staff” or “Direct Support

Staff". Although participants reported completion of training programs about TBI, programs that had a focus towards communication were limited. The participants as a group were knowledgeable about communication difficulties of individuals with TBI and useful communication strategies and all of the respondents recognized that individuals with TBI suffer socially due to their injury. Overall, there was a high level of perceived self-confidence in their ability to communicate effectively with individuals with TBI, although participants were also still open to receiving additional communication training. The two most commonly preferred forms of training included an in-person seminar or an online training format. This paper discusses the implications for future training of these professionals in both direct support and administrative positions.

KEY WORDS: traumatic brain injury, caregiver, training, communication, speech-language pathology

Table of Contents

Literature Review

Prevalence and Consequences of Traumatic Brain Injury

Traumatic Brain Injury (TBI) is defined by the Centers for Disease Control and Prevention (CDC) as an injury which is "caused by a bump, blow, or jolt to the head" or by a penetrating object "that disrupts the normal function of the brain" (Centers for Disease Control and Prevention [CDC], 2016b). The most common causes of TBI are falls, unintentional blunt traumas, motor vehicle accidents, and assaults, while the most at risk populations include people over the age of 65, young children, and men across all age groups (CDC, 2016b). The CDC calculated the total combined rate of emergency department visits, hospitalizations and deaths related to TBI to be approximately 823.7 per 100,000 people in the year 2010 (CDC, 2016a). While the overall yearly incidence of TBI is substantial as calculated by medical treatment statistics, the incidence of death within this population is relatively low with only 17.1 deaths per 100,000 (CDC, 2016a). This means that a large proportion of the population who suffer a TBI survive the initial injury and are left to cope with the long-term effects of TBI for the remainder of their lives.

The nature and severity of long-term deficits following TBI depend in part on the severity and location of the injury, comorbid health conditions, and secondary conditions developed as a result of the injury, such as brain swelling (Constantinidou & Kennedy, 2016). Although the specific resulting deficits vary widely between individuals and are largely unpredictable, there are some broad areas of physical and cognitive functioning that are commonly affected in populations who have suffered a TBI. A study by Hoofien, Gilboa, Vakil, and Donovick (2000) looked into long-term psychosocial and mental functioning of 76 participants approximately 10-20 years after receiving a traumatic brain injury. The

researchers assessed functioning across the four domains of participants' vocational abilities, social lives, role within their families, and capacity to complete activities of daily living independently. It was found that independence in activities of daily living seemed to cause the least distress for individuals and families in the long-term and was the only domain that was more closely related to intellectual abilities than psychiatric symptoms. On the other hand lack of social functioning caused the most distress for participants due to feelings of loneliness and isolation (Hoofien et al., 2000). Therefore, even though people who have suffered a TBI can experience long-term physical consequences such as seizures, motor deficits, visual and auditory problems and more, it appears that intervention focused on psychiatric and cognitive functioning may provide more benefit to the person with TBI (American Speech-Language-Hearing Association [ASHA], 2016b).

Role of Speech-Language Pathologists

Speech-language pathologists (SLPs) can provide intervention to people with TBI that may have great impact on their social functioning. According to the American Speech-Language-Hearing Association (ASHA) an SLP's role with this population is to assess and diagnose "speech, language, cognitive-communication, and swallowing disorders associated with TBI" and "develop and implement treatment plans involving direct and indirect intervention methods" to make these areas functional (ASHA, 2016a). In a review by Togher, McDonald, and Code (1999) it was noted that Hagan (1984) described how cognitive impairments that are common among the TBI population such as "attention, memory, sequencing, categorization, and associative abilities are seen to result in an impaired capacity to organize and structure incoming information, emotional reactions, and the flow of thought" which then "cause a disorganization of language processes" (as cited in

Togher et al., 1999, p. 5). Cognitive impairments of this sort are often characteristic of TBI due to injuries commonly impacting the frontal lobe of the brain where these functions typically operate (Constantinidou & Kennedy, 2016; Togher et al., 1999). Deficits in these areas of cognition do not impact language alone, but also affect the ability of individuals to act appropriately in social situations. Ylvisaker (2006) described how "Traditional Social Skills Intervention" is often not appropriate for this population due to impaired cognition. He stated that traditional intervention assumes that people with TBI "(1) lack knowledge of relevant social rules, roles and routines, (2) are motivated to change their social behavior, (3) possess the capacity to transfer skills acquired in a training setting to varied real-world application settings, (4) modify their behavior in response to planned contingencies, and (5) are reasonably self-regulated" (Ylvisaker, 2006, p. 248). However, people with TBI who struggle socially are characteristically not well regulated, do not always transfer knowledge to practical life application, and may not be aware of how their behavior affects others (Ylvisaker, 2006). Therefore with this population it is beneficial for SLPs to provide treatment creatively and think beyond traditional intervention.

One way that SLPs have explored providing social skills intervention for individuals with TBI beyond traditional methods is by also training the communication partners of these individuals. All conversations involve at least two participants and each participant must assume a large responsibility for the development of the conversation. It is likely that communication partners of individuals with a communication difficulty as is common in people with TBI would have to take even more responsibility than what would be necessary in a conversation with a typical communication partner. In order to prove the potential effectiveness of this type of training researchers first needed to evaluate how people with TBI

communicate with various partners. One valuable way to examine how individuals with TBI and partners interact is by using conversation analysis. Unlike formal tests, this form of analysis allows evaluation of communication as it occurs which permits SLPs and researchers to be more precise with their interpretations and avoid applying preconceived theories to language samples (Friedland & Miller, 1998). Conversation analysis is especially beneficial because it takes into account both communication partners contributions to the conversation as well as the importance of context, and therefore allows researchers to see how a person with TBI's performance may change depending on communication partner (Friedland & Miller, 1998). Conversation analysis also provides insight into pragmatic aspects of communication which are most important for communicative success and which also tend to be an area that is most affected in the TBI population due to impaired cognitive skills (Friedland & Miller, 1998). A study by Togher, Hand and Code (1997) determined the ten pragmatic behaviors demonstrated by individuals with TBI that are most often judged as inappropriate by others. These included prosody, intelligibility, topic change, topic introduction, topic selection, quantity/conciseness, topic maintenance, vocal intensity, specificity/accuracy, and facial expression. The adapted Kagan scales (Togher, Power, Tate, McDonald & Rietdijk, 2010a) are a tool that researchers have used to analyze conversations of individuals with TBI. The Kagan scales were originally used to evaluate conversations with people who have aphasia, but were adapted to use with people with TBI by Togher et al. (2010a) based on important conversational support principles that are specific to the TBI population. The scales are used by raters who judge the person with TBI on a series of actions that fall under the broad category of their Measure of Participation in Conversation (MPC) and their conversation partner based on their Measure of skill in Supported

Conversation (MSC) on a 9 point scale with half-point increments (Togher et al., 2010a). Refer to Appendix A for the full scoring criteria and subcategories of the adapted Kagan scales. The MPC provides SLPs with valuable information regarding how the person with TBI conveys information in a conversation, takes turns, and maintains or changes topic among other information, however perhaps the even more valuable information available with use of these scales when considering how communication partners attitudes and behaviors affect the person with TBI is presented through the MSC (Togher et al., 2010a). The MSC holds the communication partner accountable for acknowledging and revealing the competence of the person with TBI through their use of cognitive supports, scaffolding and the principles of collaboration and elaboration (Togher et al., 2010a).

Impact of Participants and Context of Conversation

When considering whether communication partner training would be beneficial researchers first had to gather data about the ways that conversation partners commonly interact with people with TBI and how their behavior may change based on the nature of their relationship (Togher et al., 1997). The study by Togher et al. (1997) utilized a method of discourse analysis called exchange structure analysis. The concept behind exchange structure analysis is that a series of information units called moves make up each larger exchange (Togher et al., 1997). There are moves, which ask for or provide information, called synoptic moves and moves that negotiate meaning called dynamic moves (Togher et al., 1997). Moves can also be categorized based on the power structure in the conversation, so if the speaker is providing information they are considered the primary knower (K1) and if they are requesting information they are the secondary knower (K2) (Togher et al., 1997). Analyzing a transcript in this way allows researchers to examine how information is flowing

in the conversation, identify any breakdowns, and decide who is taking control of the exchange. Togher et al. (1997) found that the communication partners (therapist, mother, police person) generally gave more information to the control subjects than the subjects with TBI, the therapists and mothers commonly used teaching moves with TBI subjects and were less likely to ask them for information than they were of the control subjects, and the police actually requested more information from the TBI participants than controls. These interactions varied in part because of the differences in familiarity of the participants and communication partners as well as the perceptions of the various communication partners regarding this population (Togher et al., 1997). A single case study by Togher, Hand and Code (1996) following the same design as the Togher et al. (1997) study suggested that making communication partners more aware of possible behaviors such as taking control of the conversation and unnecessarily checking details may allow the person with TBI to take a more equal role in conversations.

It becomes apparent that the context of a conversation including the relationship between the participants as well as the specific purpose of the conversation impact the performance of the person with TBI in the conversation. A study by Togher (2000) included seven participants with TBI and seven control participants who had severe spinal cord injuries. Each participant was placed in an information-giving session with two teenage boys who were completing a driving safety course and tasked with learning about and comparing the effects of brain and spinal cord injuries. Each participant with TBI or a spinal cord injury was also included in an information-requesting session where they could ask the researcher questions about the study. Togher (2000) found that the TBI and control participants gave similar amounts of information in their information-giving sessions as well as requested and

received similar amounts of information from the researcher in their information-requesting session. This study indicates that people with TBI may be able to perform similarly to people who have not suffered a TBI in interactions if they are provided with an appropriate context. Togher (2000) suggests that conversation partners can empower the person with TBI to take on a greater role in the conversation by "taking less control over turn taking, giving the client the right to determine topics, reducing the use of specialized vocabulary, reducing the number of teaching exchanges, asking real questions, reducing checking behavior and following up comments by the person with the TBI" (p. 385-386). In a similar study by Togher, Taylor, Aird, and Grant (2006) a 47-year-old man with TBI was placed into three speaking conditions where he was asked to have an unstructured conversation, request information, and give information. Each of these conditions were completed with his therapist, a peer who also suffered a TBI, and a group session with others with TBI as conversation partners. The person with TBI was able to best give information during the unstructured conversation with the therapist and the information giving session with the group, and he requested the most information from the therapist during the information requesting session (Togher et al., 2006). However, he seemed to have the most equal interaction with the TBI peer, thereby reflecting their similar status in the conversation (Togher et al., 2006). Tu, Togher and Power (2011) examined the functioning of a 19-year-old male with TBI across three discourse tasks including a casual conversation, a purposeful conversation, and a problem-solving task with his mother and male caregiver independently. Their conversations were analyzed using exchange structure analysis and the performance of the person with TBI, his mother and his caregiver were rated both by independent observers as well as by themselves in self-reflection. One important finding of Tu et al. (2011) was

that the mother responded to all of the TBI participant's requests for clarification and asked him questions to expand his suggestions during their purposeful conversations and problem solving tasks. The mother therefore provided a higher level of support than the caregiver who only responded to the TBI participant once out of the nine times he provided information during the purposeful conversation, challenged every solution to the problem solving task that the TBI participant proposed, and rarely asked the TBI participant any questions during any of the discourse tasks (Tu et al., 2011). The researchers hypothesized that the caregiver had a lower metacognitive ability to be able to participate in the structured conversations and support the TBI participant's conversation behaviors. Therefore training communication partners should focus on differentiating between different discourse tasks to promote appropriate performance specific to each, and on developing the metacognitive skills of both the person with TBI and their communication partner (Tu et al., 2011).

Training Communication Partners

One of the first research studies regarding training communication partners of people with TBI was conducted by Togher, McDonald, Code and Grant (2004). In this study police officers were selected as the communication partner to be trained specifically on how to interact with people with TBI during service encounters due to their poor performance when compared to the other communication partners of the therapist, mother, and bus timetable information service in the Togher et al. (1997) study. In the Togher et al. (1997) study the police officers frequently checked the accuracy of the information the person with TBI provided, gave them less information, used slower speech production and some patronizing comments with the person with TBI, all of which behaviors were not present with the control subjects. Service inquires recorded during the pre-training stage of the Togher et al. (2004)

study found that police officers often struggled with initially establishing the purpose of the service inquiry regarding the nature of the request, confusing the service centered conversation with a casual conversation and not restricting the person with TBI from introducing unrelated topics, and with finally ending the interaction by closing the call. Therefore training for the police officers included detailed information regarding TBI, information about how communication interactions vary based on context, specific skills needed for the context of a telephone inquiry based specifically on the skills that needed improvement during the pre-training inquiries, and then finally role-play with individuals with TBI and feedback (Togher et al., 2004). The police officers' behaviors during telephone service inquiries showed improvement during the recorded post-training inquiries and they demonstrated how their newly acquired skills supported and enabled people with TBI to have a more appropriate interaction. Learning detailed information regarding TBI as well as learning the generic structure of a service inquiry interaction were judged by the police officers to be the most beneficial part of training (Togher et al., 2004). The structure of this training program provided police officers with a good understanding of their specific role in conversations as the communication partner of a person with TBI (Togher et al., 2004).

One training program that has been developed for use with communication partners in a group setting is called TBI Express (Togher & Power, 2010). It is designed to be delivered over a period of 10 weeks with 2.5 hour sessions each week (Togher & Power, 2010). The program is broken up into 8 topics and covers important skills such as appropriate question asking, elaboration, and collaboration (Togher, Power, McDonald, Tate & Rietdijk, 2010b). See Appendix B for a breakdown of each topic and their corresponding session numbers. The TBI Express training program emphasizes certain goals for communication partners

which include viewing a conversation as a chance to collaborate or share ideas and reach a common understanding as well as a chance to elaborate or expand topics of information (Togher et al., 2010b). Other goals include using thinking supports such as writing in daily conversation, asking true and interesting questions instead of testing questions where the answers are already known, and giving positive and specific feedback to the person with TBI when they participate in a successful conversation (Togher et al., 2010b). Collaboration is one of the most important goals because it helps both participants in a conversation to approach the conversation with the right mindset of a positive event in which they must both assume an active role. Togher (2010) describes collaboration as "a way of 'sharing the floor' in a conversation, making sure that each person contributes as much as they can in the situation, supporting the person with brain injury to participate as much as possible" (p. 143). Ylvisaker, Sellars and Edelman (1998) originally developed the five key features of collaboration which include collaborative intent, cognitive support, emotional support, positive question style, and collaborative turn taking (as cited in Togher, 2013). These five features mean that the communication partner needs to convey an attitude that the conversation is an activity that they do together, that they will provide supports to make the conversation easier, that they acknowledge the person with TBI's concerns and difficulties, that they are truly interested in what the person has to say, and that they are interested in equally sharing the conversation by taking turns (Togher, 2013).

The active involvement and support of the communication partner in conversation is imperative in the promotion of appropriate performance for the person with TBI. Research has concluded that social skills is one area of skills that may improve with treatment following TBI; however, when treating the person with TBI alone improvements may be

limited due to cognitive impairments that limit learning and implementation of skills (Togher, McDonald, Tate, Power & Rietdijk, 2009). Togher et al. (2009) explain that "the International Classification of Functioning, Health and Disability (ICF; WHO, 2001) has highlighted the need for interventions which aim to increase an individual's participation in their (people with TBI's) life situation, and (that) there is potential to achieve this through enabling communication partners to provide supports which maximize opportunities for people with TBI to have successful communicative interactions" (p. 190). One study that provided evidence that training communication partners along with the person with TBI might be more efficacious than training the person with TBI alone was conducted by Togher, McDonald, Tate, Power & Rietdijk (2013). Togher et al. (2013) sorted the study participants into groups, which included a joint training group where both the person with TBI and their everyday communication partner received intervention, a solo group where only the person with TBI received intervention, and a control group where no intervention was provided. The joint and solo groups both received intervention based on the TBI Express treatment program where they completed 2.5 hours of training in a group setting with about 10 or 5 participants respectively, and 45-60 minutes of individual intervention with a therapist that involved only one person with TBI at a time, or that person and their communication partner if they were involved in the joint group (Togher et al., 2013). Each participant with TBI was evaluated using a variety of assessments regarding their working memory, processing speed, new learning, executive functioning, and cognitive-linguistic function before the trial began to make sure that participants in each of the groups had similar abilities (Togher et al., 2013). The adapted Kagan scales were used to assess the conversations of all participants including communication partners in the study before training began, after training was completed, and

six months after the training ended (Togher et al., 2013). Togher et al. (2013) compared the results of the assessments and found significant differences in the performance of those involved in the joint and control groups, however no significant differences were found between solo and control groups. The assessments completed six months after treatment showed that the participants maintained the skills that they had gained from training when compared to the assessments conducted directly after training. The assessments conducted after the training program showed that communication partners who had participated in the joint group showed significant improvement in "acknowledging and revealing the competence of the person with TBI . . . in casual conversations, but not in purposeful conversations" (Togher et al., 2013, p. 45). However, casual conversations were also likely more frequently used and practiced between the communication partners and so improvements in that area were likely more beneficial anyway (Togher et al, 2013).

Efficacy of Training

In a similar study participants were allocated to either joint or control groups (Sim, Power & Togher, 2013). Casual conversations were judged by Sim et al. (2013) both before and after training using exchange structure analysis and productivity analysis. Communication partners who participated in training had individualized goals such as waiting for the person with TBI to respond to questions or comments, acknowledge the person with TBI's contributions to the conversation and observe both their verbal and non-verbal behavior, wait for their own turn in conversation and not speak over the person with TBI, and provide supports and scaffolding to the person with TBI to assist them in organizing their thoughts (Sim et al., 2013). It was found that trained communication partners showed a significant reduction in the amount of testing questions that they used, and they improved on

their ability to track and encourage information provided by the person with TBI (Sim et al., 2013). One study by Mann, Power, Barnes & Togher (2015) emphasized that examining specific types of change in questioning behavior is important for determining their overall benefit. Mann et al. (2015) compared four pairs of people with TBI and their communication partners after they had completed the TBI Express training program. Two of the pairs showed the most improvement following training as part of a larger trial as judged by the adapted Kagan scales, while the other two showed the least among the whole group. One of the pairs who improved the most had trouble generating topics of conversation before they received intervention, however after completing the TBI Express program both partners used questions to successfully introduce and expand topics (Mann et al., 2015). The other pair who showed the most improvement initially struggled because the communication partner used questions to test the person with TBI's knowledge and memory (Mann et al., 2015). However after intervention the communication partner used true questions to learn about the person with TBI's life instead of asking questions that she already knew the answer to (Mann et al., 2015). One of the pairs who showed the least improvement also had trouble with the communication partner asking testing questions that limited topic development before receiving intervention. After intervention the communication partner asked questions to develop the topic, but often didn't allow the person with TBI to contribute much before reassuming the role of speaker therefore limiting topic development (Mann et al., 2015). The other pair who also improved the least also initially asked testing questions. After intervention the communication partner tried to develop topics through the use of questions, but was not sensitive to the person with TBI not wanting to talk about certain topics and often repeated the same questions (Mann et al., 2015). This study shows that programs

designed to train communication partners to support a person with TBI are effective as proven by various assessments, however individual results do vary. Therefore, an ideal training program would take into account the individual needs of the participants and would include feedback on performance after intervention to address any continuing problems. Although these modifications may be hard to incorporate into some training settings, they are still important to take into consideration.

Efficacy of training programs for communication partners has been proven not only through analysis of conversations by independent observers, but also through personal reflections of those who participate in the training as a communication partner or a person with TBI (Togher, Power, Rietdijk, McDonald & Tate, 2012a; Togher, McDonald, Tate, Rietdijk & Power, 2016; Behn, Togher & Power, 2015). Togher et al. (2012a) evaluated some of the participants who were involved in the study described by Togher et al. (2013). Participants in the joint and solo groups were interviewed after completing the TBI Express program to gain qualitative feedback about the program and perceived results (Togher et al., 2012a). Togher et al. (2012a) found that participants in both the joint and solo groups noted improvements regarding "collaborating in order to share conversations better with others, starting conversations, using an increasing range of topics and elaborating in order to keep conversations going" as well as "in the areas of clarity, organization, and efficiency of communication" (p. 1566). Participants with TBI reported increased confidence, while communication partners reported more confidence in supporting the person with TBI as well as with letting them be more independent in social situations when able (Togher et al., 2012a). Some communication partners felt confronted and uncomfortable when they received feedback during training, and they made the suggestion that the trainers should

acknowledge these feelings as normal (Togher et al., 2012a). The participants found many aspects of the training to be beneficial "including taping of conversations, written notes of the course content, role plays, practical demonstrations, feedback, home practice, (and) modelling of communication skills by peers and support from peers" (Togher et al., 2012a, p. 1571). Participants with TBI in the joint group appreciated the participation of their communication partner in training and many communication partners and participants with TBI reported improvements in their relationships with each other (Togher et al., 2012a). The Togher et al. (2013) study was also analyzed using the La Trobe Communication Questionnaire (LCQ) as a measure to determine participants' impressions of improved skills following training (Togher et al., 2016). The LCQ has 30 items designed to assess perceived communication ability, as well as two forms, one designed for self-report and the other designed for completion by close communication partners (Togher et al., 2016). The participants in the joint group reported significantly more improvement as determined by the LCQ following treatment when compared with the solo and control groups, however the solo group did report more improvement than the control group (Togher et al., 2016). At the assessment six months following completion of the training both the communication partners and participants with TBI in the joint group reported continued positive change, while the participants with TBI in the solo group also reported positive change however their communication partners did not (Togher et al., 2016). This study suggests that communication training designed to improve social functioning best fulfills its intended purpose when communication partners are involved in the training as judged by the people who participate in the training.

Relationship of Paid Caregivers as Communication Partners

Most of the research regarding training communication partners to provide support in conversation such as Togher et al. (2013) has included everyday communication partner participants who are primarily related to the person with TBI either as a parent, or spouse. While a few paid caregivers have been included in studies such as these, there have been few studies that primarily focus on developing the skills of employed caregivers (Togher et al., 2013; Ducharme & Spencer, 2001; Behn, Togher, Power & Heard, 2012). Sometimes following a TBI people will live in a long-term residential care facility such as a rest home or group home as their primary residence, others may attend day programs, or simply have a paid caregiver to provide assistance in their home or community (McCluskey, 2000). In any of these settings people with TBI will interact with paid staff or caregivers as communication partners, and the nature of their relationship with these people may vary widely from the relationships expected with family members (McCluskey, 2000). McCluskey (2000) interviewed five individuals with TBI and their paid caregivers who provided services in their home and community to determine the nature of their relationship and the primary roles that caregivers are expected to assume. She found that the caregivers most often had to take on the roles of attendant, protector, friend, coach, and negotiator. According to the National Joint Committee for the Communication Needs of Persons with Severe Disabilities (NJC), all people regardless of disability have a certain set of communication rights as laid out in the Communication Bill of Rights, one of which states "the right to have access to environmental contexts, interactions, and opportunities that promote participation as full communication partners with other people, including peers" (National Joint Committee for the Communication Needs of Persons with Severe Disabilities [NJC], n.d.). Paid caregivers

therefore have the responsibility to practice appropriate communicative interactions and relationships with the person with TBI as well as facilitate those interactions with others in the community (McCluskey, 2000).

Research Regarding Caregiver Training

A study by Ducharme and Spencer (2001) focused specifically on training paid caregivers of people with TBI to improve their teaching and interaction skills with the person with TBI. The research participants' skill in demonstrating adequate teaching skills was judged based on five categories including providing clear task instruction, using less intrusive prompts, timing prompts correctly, using physical prompts correctly, and using contingent social approval (Ducharme & Spencer, 2001). Their interaction skills to promote appropriate behavior of the person with TBI was based on their ability to use reinforcement correctly, to use a graduated approach by adapting the environment, and to use extinction correctly by not reinforcing a problem behavior (Ducharme & Spencer, 2001). The caregivers were trained in a group workshop setting that included modeling of skills being taught, roleplay in possible situations where they would be used, and valuable feedback (Ducharme & Spencer, 2001). Although the training conducted by Ducharme and Spencer (2001) was not solely related to improved communication skills, the participants did show improvement on some measures related to communication such as providing clear task instruction, correctly timed prompts, and appropriate reinforcement. Due to the overall improvement of study participants across multiple skills Ducharme and Spencer (2001) concluded that utilizing modeling and feedback greatly enhanced the training program.

Behn et al. (2012) conducted a study aimed specifically at improving the communication skills of paid caregivers in a residential rehabilitation center. Ten

participants were included in the study, five of which completed the training program while the other five comprised the control group. Five people with TBI also participated in the study by having filmed structured and casual conversations with the caregiver participants both before and after the training, although no participants with TBI were directly trained on any communication strategies. The caregivers who completed training were trained using an adaptation of the TBI Express program that focused especially on elaboration and collaboration techniques during training sessions that comprised 17 hours over an 8 week period (Behn et al., 2012). The training utilized "group discussion, modelling, role-play, feedback, rehearsal, positive reinforcement and written exercises" and situations that would commonly occur in that workplace with the TBI population were introduced such as "planning a visit into the community, (having a) chat following an aggressive incident, (and) interacting with staff in a coffee shop" (Behn et al., 2012, p. 1706). Post training evaluation showed that the caregiver participants who completed training used more "natural, adult-like, and less patronizing" speech with people with TBI, and they helped to increase the person with TBI's participation by "introducing topics of interest, adding information to maintain the conversation and asking open-ended questions that encouraged extended responses" (Behn et al., 2012, p. 1710-1711). Even though the trained paid caregivers showed substantial improvement in their skills during structured conversations, there was no significant improvement in their casual conversations (Behn et al., 2012). However, these results are understandable due to the nature of the relationship, structured conversations are more common in a residential rehabilitation centers and casual conversations may be judged as inappropriate to the professional relationship in that environment (Behn et al., 2012). There were also no improvements on measures directly related to the participants with TBI's

performances, although they received no training so the lack of direct effect on their behaviors is understandable. Behn et al. (2012) found that there was no significant difference in the follow up measurements conducted directly following training and those gathered six months later therefore showing that improvements were maintained among caregivers. Behn, Togher and Power (2015) decided to gather information about the caregivers' experiences of the training program conducted in Behn et al. (2012) by conducting semi-structured interviews before and after the training. The reflections regarding the training program were mostly positive. The caregivers were familiar with information regarding TBI before training due to the nature of their job, but they found that the information about how impaired cognition can impact conversation to be especially useful in changing their approach in conversations (Behn et al., 2015). They became more self-aware about how their behaviors impact the person with TBI's opportunities in a conversation and they became more confident and comfortable communicating with people with TBI and enjoyed those interactions more (Behn et al., 2015). They agreed that training more of their coworkers would be beneficial and emphasized the importance of training for the diversity of possible communication profiles of those who have a TBI such as those who are very "passive and withdrawn" as well as those who are "verbose and egocentric" (Behn et al., 2015, p. 1558). They appreciated the practical learning aspects of training such as roleplay and viewing videotapes more than they did the lectures and they found some of the terminology difficult to understand (Behn et al., 2015). Considerations such as reducing the amount of specialized terminology is especially important for this population of caregivers given their demographic characteristics. The caregiver participants in the Behn et al. (2012) study were all female, seven out of the ten were under age 30 and four of the ten had not

worked as a caregiver prior to their employment at that rehabilitation center, they did not have professional qualifications, and their IQ was in the low-average range. An article covering the importance of training communication partners of individuals with severe disabilities by Sack and McLean (1997) took into consideration the demographic information and opinions of caregivers of people with developmental and intellectual disabilities to present suggestions on developing a communication program appropriate for their level of specialization and available time in their workplace. They made suggestions regarding decreasing the amount of professional jargon in the training program, focusing more on concrete examples and less on abstract ideas, and reducing the amount of information to only what would be beneficial in that role and not everything that a professional could share (Sack & McLean, 1997). Sack and McLean suggest that training should be structured so that it can be delivered by a nonprofessional over a flexible amount of time and organized in short topics. It should also provide opportunities for practicing skills, applying them to relevant situations and receiving feedback (Sack & McLean, 1997).

Training Programs Available in North Carolina

To determine what types of training are most needed in a particular area, it is first important to examine prevalence of TBI and services available in that particular area. According to a brief about traumatic brain injury in North Carolina by Hooper et al. (2015) there were approximately 76,708 occurrences of TBI in the year 2012 alone. In North Carolina resources relating to TBI are managed through the Department of Health and Human Services' Division of Mental Health, Developmental Disabilities and Substance Abuse Services (DMH/DD/SAS) (North Carolina Department of Health and Human Services [NC DHHS], n.d.-a). In 2007 the department conducted a needs assessment by surveying

TBI survivors, their families and friends, and service providers about areas that were lacking in North Carolina that would be beneficial to the TBI population (Hooper et al., 2015). One identified need was for greater "education of professionals working with individuals who have sustained a TBI" (Hooper et al., 2015, p. 84). The North Carolina TBI program received a grant that had four main components, one of which was to "offer statewide training regarding TBI for the behavioral health and primary care systems" (NC DHHS, n.d-a). One way that this training is now being offered is through the Brain Injury Association of North Carolina (BIANC) who offers training to professionals and service workers in North Carolina to become Certified Brain Injury Specialists (CBIS; Brain Injury Association of North Carolina [BIANC], 2016). According to a list of nationwide CBIS published on August 1, 2016, there were a total of 252 CBIS in North Carolina who were associated with a variety of organizations including but not limited to hospitals, rehabilitation services, and community programs (Brain Injury Association of America [BIAUSA], 2016a). According to the Brain Injury Association of America, to become a CBIS one must "pass a standardized exam, possess a high school education, and complete 500 hours of paid work experience with brain injury in the past 3 years" (BIANC, 2016). Areas of assessment on the exam include knowledge of "TBI and diagnostic imaging; medical, physical, cognitive neurobehavioral, and psychosocial consequences of injury; TBI in pediatrics and adolescents, as well as aging with a brain injury; concussions and mTBI, as well as disorders of consciousness; rehabilitation philosophy, outcome measurement, and care management; effect of injuries on families; cultural, gender, and sexuality issues; military populations; neuropsychology; and participation and return to work" (BIAUSA, 2016b). There are training programs available to assist candidates in becoming familiar with these areas, but they are not required (BIANC,

2016). One such training program is available in North Carolina as an online program, which consists of seven modules called NC TBI (NC DHHS, n.d.-b). The training is free and available to anyone although it is especially intended for "Local Management Entities (LMEs), vocational rehabilitation or independent living offices, educators, case managers, substance abuse or mental health professionals, social security or social services professionals, advocacy or support agencies, or anyone else who serve(s) people with brain injury" (NC DHHS, n.d.-b). Modules consist of information organized by topic that is presented in a series of slides or in multimedia formats such as videos or podcasts and then each module ends with questions in a quiz format (NC DHHS, n.d.-b). If one completes all seven modules of the online training a printable certificate is awarded (NC DHHS, n.d.-b). The BIANC also suggest an online video series called Brain Injury 101 to review for the CBIS exam (BIANC, 2016). It is a series of five videos that are designed primarily to provide family members of people who have suffered a TBI with information regarding the brain, the impact that injury can have, resources that are available, and suggestions for gaining support (Shepherd Center, 2017).

Although neither the online North Carolina TBI training program nor the Brain Injury 101 program are focused specifically on communication, the NC TBI program does contain some information related to communication and aspects of cognition that may affect communication (NC DHHS, n.d.-b). It covers areas such as slowed processing and memory impairments, impaired attention and comprehension, difficulty with abstract reasoning, problem solving, planning, and initiation both by describing problems that the person with TBI might have related to each impairment as well as suggested strategies that the conversation partner can adopt to try to assist them (NC DHHS, n.d.-b). Some of these

suggestions include things such as using memory aids, giving the person with TBI time to process information or requests, reducing environmental distractions, using concrete terms, and breaking down tasks (NC DHHS, n.d.-b). The training also emphasizes the importance avoiding patronizing the person with TBI and instead treating them with respect as an equal (NC DHHS, n.d.-b). While these are all beneficial tips the training does not demonstrate the skills in a practical way, there is no modelling and no opportunities for the person completing the training to personally practice any of the skills or receive feedback on their performance (NC DHHS, n.d.-b). One program that does adequately model skills related directly to communication is the online version of the TBI Express program used in the Togher et al. (2013) study (Togher, McDonald, Tate, Power, Ylvisaker, & Rietdijk, 2012b). The program includes an introduction that explains the usefulness of training communication partners of people with TBI as well as two sets of videos that emphasize the concepts of collaboration and elaboration (Togher et al., 2012b). Both the sets of videos about elaboration and collaboration start out with an example of a conversation that does not utilize the techniques well. They show how the conversation can break down between the person with TBI and the communication partner. Then there is a video of the communication partner alone explaining how their communication with the person with TBI has changed since the injury, what struggles the person with TBI has that make the conversation difficult, and finally some new techniques that they have learned that are helping to change their conversations in a positive way. Lastly there is a video in each set that demonstrates the conversation partner utilizing the positive skills that they learned in a conversation with the person with TBI over the same topics that were covered in the original video with ineffective communication (Togher et al., 2012b). The TBI Express website also contains printable resources that include transcripts of

each of the conversations in the videos with commentary about the communication partner's performance and what effect they have on the person with TBI as well as a communication toolkit that covers the collaborative and elaborative strategies taught in the video (Togher, 2011a; Togher, 2011b; Togher, 2011c). The TBI Express program is advertised as being designed for friends, families, and caregivers of people with TBI; however both conversation partners portrayed in the video are in familial roles to the person with TBI either as a mother or a wife (Togher et al., 2012b). The conversational tips are still relevant to people in a caregiving role, but the types of conversations portrayed may not be those that are most typical in a caregiving relationship.

Limitations of Current Resources

There has been much research suggesting that the conversational behaviors of communication partners of people with TBI and the context of their conversational exchanges greatly affects the opportunities and performance of the person with TBI (Togher et al., 1996; Togher et al., 1997; Togher, 2000; Togher et al., 2006; Tu et al., 2011). As a result of those findings various conversation partner training trials were completed that showed benefit for both the person with TBI and the conversation partner, and under no trial did the training ever cause either person harm (Togher et al., 2004; Behn et al., 2012; Togher et al., 2012a; Sim et al., 2013; Togher et al., 2013; Wiltshire & Ehrilch, 2014; Mann et al., 2015; Behn et al., 2015; Togher et al., 2016). Given these findings it is especially important to consider providing communication training to individuals who work as caregivers to people with TBI who are often put in the role of primary communication partner with this population (McCluskey, 2000). Although there are some current widespread TBI training programs available their scope either covers much more than communication alone or they

are not geared directly towards people in a caregiving role (NC DHHS, n.d.-b; Shepherd Center, 2017; Togher et al., 2012b). Therefore it is unclear whether these programs are truly adequate or are even being utilized by the caregiver population. In order to assess the effectiveness of the current programs it would be useful to survey individuals who are employed in a caregiving role with people with TBI. The caregivers' demographic information, the training programs that they have completed, their current understanding of communication difficulties associated with TBI, common conversation contexts and purposes in their job, and their perception of their current ability to communicate with their client with TBI should all be assessed to determine how the types of training based on research could be adapted most effectively for their specific situation as a caregiver.

Method

Participants

Participants for this study were recruited indirectly. The researcher gathered a list of potential contacts from the Brain Injury Association of North Carolina (BIANC) website. The BIANC has an online resource book of services for people with TBI across the state of North Carolina sorted into categories by the type of service that is available. The researcher chose to include resources listed in the categories of "brain injury support groups", "day and clubhouse programs", "residential options", and "respite care" as it was assumed that providers of these types of services may have the most contact with people who are employed as caregivers to individuals with TBI. Approximately 80 organizations from these categories were originally on the list to contact. After eliminating some organizations from

the list to contact based on the unlikelihood of gathering intended participants from those sources, the researcher contacted around 36 organizations. Initially 19 organizations agreed to participate when the researcher asked if they would be willing to forward the anonymous survey to any paid caregivers that they knew and they provided the researcher with an email address. They were emailed with information about the study and the survey link and were asked to forward it to paid caregivers. Initial response was low so the researcher extended the deadline of the survey and sent the link to an additional 15 individuals with whom contact was not originally made with the hopes that they might participate. During the time it was active the survey yielded a total of 22 responses; however nine of the responses were unable to be included in the data set of this study due to either a lack of willingness to complete the survey, a negative answer to the qualifying question which made sure participants were members of the target population, or by contacting the researcher immediately after completing the survey to say that they realized they were not a member of the target population. A total of 13 participants' responses were included as the data set that was analyzed in this study. One of the 13 participants stopped halfway through the survey although their responses were still included for the questions that they did answer. Therefore some of the questions only have a total of 12 respondents instead of 13. Although two of the participants appeared to be caregivers related to individuals with TBI instead of people employed in a caregiving role, they answered affirmatively to the qualifying question, identifying as a paid caregiver, and therefore their responses were included in the data.

Materials

The materials of this study consisted of an online survey developed using qualtrics software. From the software an anonymous link was generated so that the survey could be

distributed via email and forwarded to other prospective participants. Responses to the survey were completely anonymous and therefore could not be tied to individual respondents. The intended purpose of the survey was to gather demographic information about people who work in caregiving roles for people with TBI, learn about their current levels of training, evaluate their understanding of communication related impairments associated with TBI, assess the nature of their interactions with individuals with TBI, and to gauge their interest in further communication training. These particular objectives were chosen after reviewing the research covered in the literature review portion of this study. Demographic information was sought to see if the demographics of the sample population surveyed through this study related to the populations of other studies that have gathered information about caregivers of people with TBI (Behn et al., 2012; McCluskey, 2000). This information related to gender, age, and specifically education could potentially be important to consider in order to develop a maximally appropriate and beneficial training program for caregivers (Sack & McLean, 1997). The researcher sought to gather information about training programs that the caregivers had already completed as a way to estimate their current expertise related to communicating with individuals with TBI and to see which training programs in North Carolina were most often utilized among the sample population (BIANC, 2016; NC DHHS, n.d.-b; Shepherd Center, 2017; Togher et al., 2016b). Another way the researcher attempted to gauge the caregivers' understanding of communicating with individuals with TBI was to ask if they could identify some communication difficulties of individuals with TBI and share some strategies that they use as the caregiver. The researcher wished to compare this information of the difficulties and skills that the caregivers would identify to the findings of other research in the field regarding what difficulties are common

and which strategies are useful (Togher et al., 1999; Hoofien et al., 2000; Togher et al., 2010b). It was hypothesized that gathering information about the caregivers' relationship to the person with TBI, their role in the conversation, and the nature of the conversation would be useful when attempting to determine how interactions with professional caregivers may differ from interactions with family caregivers for individuals with TBI. These factors regarding the nature of the conversation as well as the relationship and behavior of communication partners have proven to be important to the success of the communication interaction with individuals with TBI in other research studies (Togher, 2000; Togher et al., 2006; Togher, 2013; Togher et al., 2013; Behn et al., 2012). Finally, the researcher wished to see how the caregivers assessed their own abilities as other research studies have asked conversation partners to do (Togher et al., 2012a). One method of gauging the caregivers' confidence was to ask if they desired further training. The objectives of this study were accomplished through a series of multiple choice and free response questions on the survey. Please see Appendix C for a full list of the questions used for the survey.

Procedure

The researcher initially intended to perform statistical analysis on the responses provided by the survey participants to evaluate trends in their responses. However, the low number of respondents (only 13 total) necessitated a different approach as with such a small sample size, statistically significant findings would have had minimal power. Evaluating the responses using a descriptive qualitative analysis proved to be a more appropriate method of assessing the collected data. The questions had been carefully constructed, based on the available literature, and so the researcher was able to apply a 'Grounded Theory' approach to the qualitative description of the data. Grounded Theory is a strategy of inquiry grounded in

data (Keegan, 2012). The data is systematically gathered, and in this case was gathered through a survey that was grounded in the published literature on the topic. The collected data was then analyzed in a descriptive methodical manner, in light of the available relevant literature.

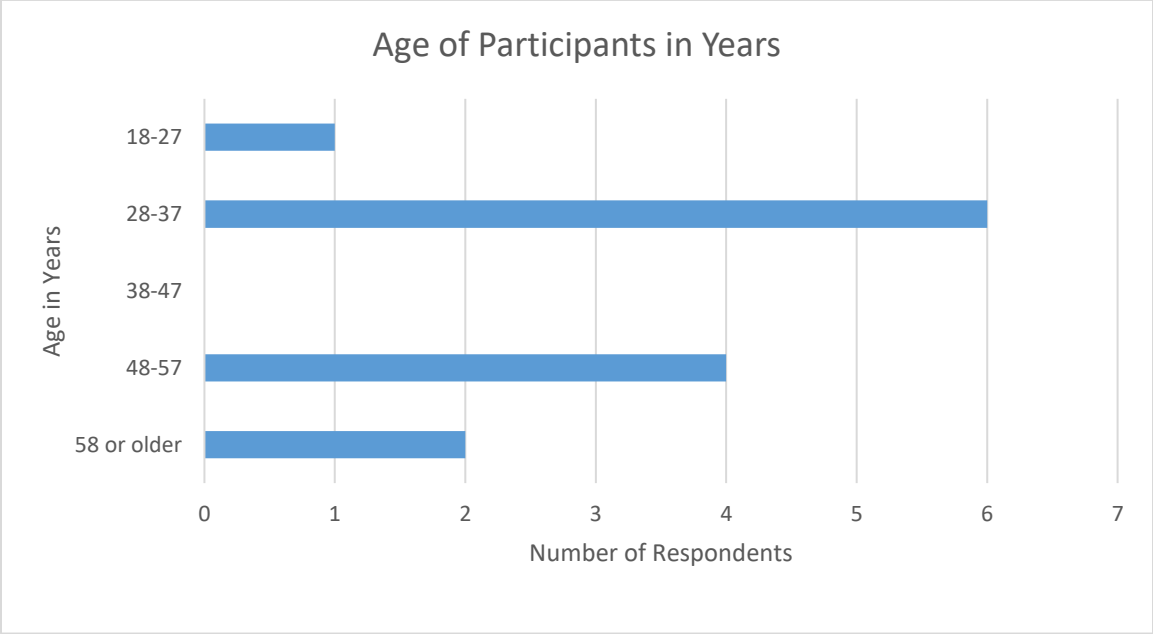
The researcher sorted the data collected, 21 questions from the survey, into nine different categories based on the type of information that they provided. The participants' responses to the questions were reported and represented using a series of figures and tables. Trends between demographics of participants and their responses to the survey were then associated and reported. The researcher systematically analyzed the data and compared the findings to other available similar research. Findings regarding participants, types of training, recognition of difficulties, strategies in communication, structure of conversational interaction, attitudes, and additional training were all reported.

Results

Participants

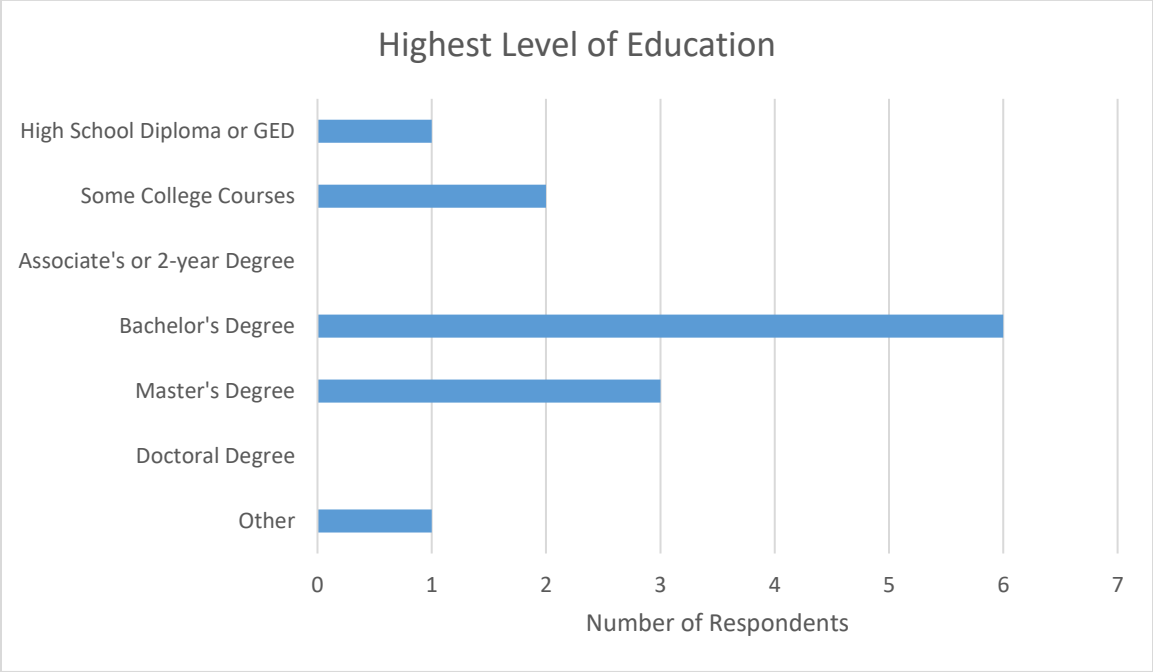
There were a total of 13 survey participants who provided usable responses. Of these 13 participants 12 were identified as female, while only 1 was male. Six of the respondents indicated that they were between the ages of 28 and 37, which made this range the largest age group among participants. The second largest age group was between 48 and 57, with four respondents falling into this category. Two respondents indicated that they were 58 or older and only one respondent was between the ages of 18 and 27. No participants were between the ages of 38 and 47.

Figure 1: Age



The majority of the participants indicated that their highest level of education was the completion of a bachelor's degree with six respondents belonging to this category. Three respondents indicated that they had a master's degree, while two said that they had completed some college courses. Only one respondent had completed high school or a GED program as their highest level of education. One respondent selected the option to specify a different level education and stated that they were a licensed practical nurse (LPN). No respondents had an associate's or 2-year degree as their highest level of education, nor did any have a doctoral degree.

Figure 2: Education

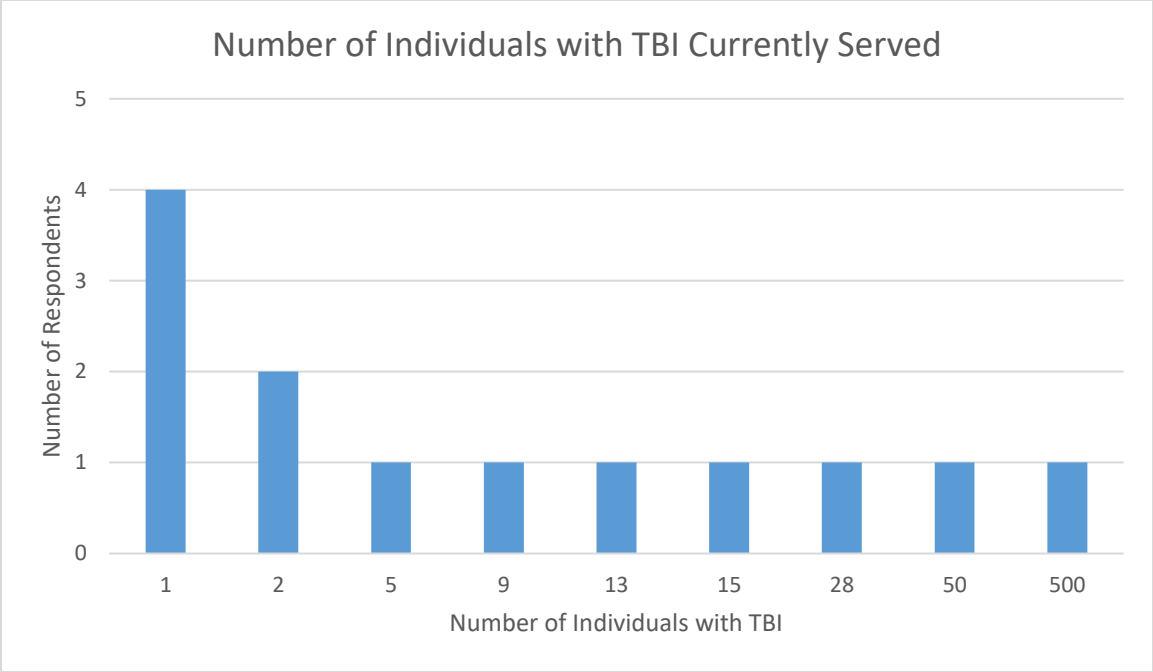


Participants were also asked about the number of years they had been employed working with individuals who have experienced a TBI. Their responses ranged from 1 year up to 22 years, although most had not been employed for more than 7 years with this population. Two people indicated that they had been employed for 3 years as did two other people for both of the categories of 4 years and 5 years. Therefore, 6 of the 13 respondents had been employed between 3 to 5 years. Only two respondents had been employed for less time, one for only 1 year, and the other for 2 years. One person indicated that they had been employed for 6 years, and one person indicated seven years. These responses show that only 3 out of the 13 participants had been employed in jobs related to serving people with TBI for more than 7 years. Of these three, one had been employed for 12 years, one for 20 years, and one for 22 years.

Figure 3: Years Employed

When asked how many individuals with TBI the participants served in their current jobs most responded that they only served one or two individuals. More specifically, four respondents only served one individual in their current job while two respondents served two individuals with TBI each. The remaining participants all varied in the number of individuals that they served by responding that they each currently served 5, 9, 13, 15, 28, 50, or 500 individuals with TBI. From these responses it is clear that there are some outliers included in this data set and it is probable that the respondent serving 500 individuals is not likely providing direct care to all of these individuals.

Figure 4: Individuals with TBI Served



Participants were also asked to identify in which settings they provided care to individuals with TBI as part of their employment. Three respondents indicated that they provided care in the person with TBI's personal residence (in their home). Only one participant indicated that they provided care to the person with TBI in the community (e.g. public settings or community centers). Three participants provide care in a group home setting while three also provide care in a day program setting. Five participants chose to specify a different setting by choosing the "other" option. Their responses were as follows: "in my home 24/7", "brain injury support group and rehabilitation hospital", "in hospital", "in a residential rehabilitation facility that houses 18 individuals with Brain Injury", and "program coordinator for a provider who provides services to several individuals with TBI". Table 1 includes a summary of the data that has been described regarding the participants.

Table 1: Participant Summary Data

Demographic	**Responses**	**Number of Respondents (n = 13)**
Gender	Female	12
	Male	1
Age in Years	18-27	1
	28-37	6
	38-47	0
	48-57	4
	58 or older	2
Highest Level of Education	High school diploma or GED	1
	Some college courses	2
	Associate's or 2-year degree	0
	Bachelor's degree	6
	Master's degree	3
	Doctoral degree	0
	Other (please specify): -specified: LPN (licensed practical nurse)	1
Years Employed with TBI Population	1	1
	2	1
	3	2
	4	2
	5	2
	6	1
	7	1
	12	1
	20	1
	22	1
Number of Individuals with TBI Currently Served	1	4
	2	2
	5	1
	9	1
	13	1
	15	1
	28	1
	50	1
	500	1
Setting of Care*	The person with TBI's personal residence (in their home)	3
	In the community	1
	In a group home setting	3

	In a day program setting	3
	Other (please explain) • in my home 24/7 • brain injury support group and rehabilitation hospital • in hospital • in a residential rehabilitation facility that houses 18 individuals with Brain injury • program coordinator for a provider who provides services to several individuals with TBI	5

*respondents could choose more than one option so total number of responses will exceed 13

The last question designed to gather demographic information about the participants asked them to provide their official job title. No two titles were exactly the same, however the researcher attempted to categorize the responses based on the level of the position or type of service it was hypothesized that they provide. Three of the respondents had the word "director" listed in their job title. Their job titles are as follows: "Clinical Director", "Activities Director/Admissions", and "Day Program Director". An additional three respondents had the word "coordinator" in their job titles, which included the titles of "Program Coordinator", "Project Assistant Coordinator", and "Social Work Coordinator". It was hypothesized that the six respondents who either had the word "director" or "coordinator" in their job titles were in somewhat of an administrative role within the companies where they worked. Their titles were therefore compiled into the category of "Administrative Staff" listed below. The remaining seven respondents did not have the word "director" or "coordinator" listed in their job titles and were therefore assumed to be in more

of a direct support role for individuals with TBI. Therefore job titles of "Social Worker", "Clubhouse Specialist", "CNA", "Hab Tech 2", "Alternate Family Living", "Caregiver", and "Wife/Caregiver" make up the "Direct Support Staff" category below.

Table 2: Job Titles

Administrative Staff	Direct Support Staff
Clinical Director	Social Worker
Activities Director/Admissions	Clubhouse Specialist
Day Program Director	CNA
Program Coordinator	Hab Tech 2
Project Assistant Coordinator	Alternate Family Living
Social Work Coordinator	Caregiver
	Wife/Caregiver

Types of Training

After gathering basic demographic information about the participants in the survey and their current careers, the researcher attempted to gain some insight into how professionals employed in a service role to individuals with TBI were currently trained. The researcher briefly described the requirements to become a Certified Brain Injury Specialist and then asked the participants if they had obtained this certification. Five of the 13 participants responded that they were Certified Brain Injury Specialists, while the remaining eight indicated that they did not have that certification.

The participants were then asked if they had received any training related to how individuals with TBI communicate or strategies that others could use in conversation with them and if so they were asked to describe what type of training that had been. Eight participants indicated that they had completed training of this sort while the other five indicated that they had not. Two of the participants who indicated that they had completed

training said that they couldn't remember specifics about the training except one of the participants said their training had been online while the other said they had received in person training. Another respondent who had completed training did not offer any specific details about the type of training, but instead just stated that there were "various trainers through my employer". Some of the respondents offered a few more details about the types of training they had received. For example, one participant responded simply by only stating "core training". A different participant responded that their employer had "provided preserve training that encompasses TDI [sic] within that training". Another said that they had done "Technology and TBI" which was somehow related to "different software to use". One participant mentioned that they had completed "person centered thinking", "motivational interviewing", and "various brain injury specific conferences and workshops both online and in person". Only one person said that they had completed any of the other types of training mentioned in the literature review section of this article besides the Certified Brain Injury Specialist, which was the NC TBI training. The same person also said that they had done "many webinars through DCoE" (Defense Centers of Excellence) "and BIAA" (Brain Injury Association of America) "Brain Injury conferences". It is unclear to the author which of the forms of training that were provided as a response to this question were actually directly related to communicating with individuals with TBI, and which were just related to TBI in general.

Once the participants answered the question about the types of training related specifically to communication, they were asked to identify any other types of general training they had had. The participants were not required to answer this question in order to proceed with the survey, so only 10 of the 13 total participants provided a response. Out of those

responses the most frequently present type of training was cardiopulmonary resuscitation (CPR) with 8 out of the 10 respondents having this training. A close second was first aid training with seven respondents having this training. Five of the respondents had completed nonviolent crisis intervention (NCI) training and two had completed training related to bloodborne pathogens. There were five types of training mentioned that seemed to be job specific, which included “MED Administration”, “Med Tech”, “CRC” (Clinical Research Coordinator), “Activity Director Training”, and “CNA” (Certified Nursing Assistant) training. Other specific trainings listed by one person each included “defensive driving”, “suicide prevention”, and “wandering”. One person chose to list their completion of the NC TBI training program under this question instead of under the question that asked about training related to communication specifically. This provides the assumption that only 2 out of the total 13 participants have completed NC TBI training. Two individuals listed their experience with other populations as beneficial training. One of these individuals stated that they had worked with individuals with dementia, Alzheimer’s and intellectual disabilities. The other individual said that they had completed a five day training course regarding individuals with Autism called “TEACCH”, although they had found this training useful when working with individuals with TBI as well. Finally, one respondent said that they had completed “PICK training” although it is not used in their current company. It is unclear to the author what “PICK” stands for or what areas this training covers. Table 3 summarizes the training reported as completed by the respondents.

Table 3: Training

Training Name	Number of Participants
Common Trainings	
CPR (cardiopulmonary resuscitation)	8
First Aid	7
NCI (Nonviolent Crisis Intervention)	5
Bloodborne Pathogens	2
Job Specific	
MED Administration	1
Med Tech	1
CRC (Clinical Research Coordinator)	1
Activity Director Training	1
CNA (Certified Nursing Assistant)	1
Other Specific	
Defensive Driving	1
Suicide Prevention	1
Wandering	1
TBI Specific	
NC TBI	1
Other Populations	
Experience with dementia and Intellectual Disability	1
TEACCH training (for autism)	1
Other	
PICK training	1

Recognition of Difficulties

Once it was determined how the participants were trained, the researcher sought to gather information related to how the participants recognized and perceived the communication difficulties of individuals with TBI. The researcher first asked the question "Do you believe that individuals with TBI suffer socially because of impaired communication?" in a simple yes/no response format. One of the 13 participants chose to stop the survey before reaching this question, but of the 12 who did respond, they all said yes. Therefore of the 100% of the respondents who answered this question said that they

believe that individuals with TBI suffer socially. This was the only question in the entire survey where all of the participants responded the same way.

The participants were then given an opportunity to describe some communication difficulties that individuals with TBI might experience. All 12 participants who reached this point in the survey provided a response to the question. The researcher summarized and divided the information the participants provided into individual comments and then categorized each comment based on the type of impairment it described. Comments were divided into five major areas of functioning including “Neurobehavioral”, “Cognitive”, “Language”, “Motor Speech/Voice Deficits”, and “Nonspecific” areas. There were an additional 11 subcategories under the major areas of “Neurobehavioral”, “Cognitive, and “Language” under which the comments fit. Please see table 4 below for each category and their correlating comments.

Table 4: Communication Difficulties

Major Area	Subcategory (n)*	Identified Difficulties
Neurobehavioral	Affective Changes (1)	• Flat Affect
	Irritability (2)	• Easily irritable and unable to vent frustrations • Frustrated when they are asked to repeat themselves
	Impulsivity (1)	• Poor impulse control
Cognitive	Attention (1)	• Difficulty following the conversation
	Executive Function (3)	• Trouble with initiation • Difficulty initiating conversation • Lack of organizational skills
	Information Processing (2)	• Poor listening • Caregiver must be prepared to repeat themselves and work at a pace that doesn't overwhelm the individual**
	Memory and Learning (5)	• Sometimes forgetful • Repeats conversation due to memory difficulties • Poor memory of conversation • Memory issues • Trouble with short term memory and recall
	Impaired Metacognition (2)	• Inability to express feelings on certain subject • Do not understand their own emotions sometimes
Language	Comprehension (3)	• Difficulty with concrete thinking • Trouble understanding jokes or nuance of conversation • Processing issues that cause confused speech
	Verbal Expression (9)	• Using the wrong words • Repetition in conversation embarrasses the person with TBI • Unable to express thoughts in a timely manner • Unable to articulate thoughts • Trouble with word finding

		• May say something and mean something else • Repeating themselves • Aphasia • Aphasia
	Pragmatics/Social Communication (7)	• Inappropriate comments • Social awkwardness • Lack of filter • Unable to pick up on social cues • Monopolizes the conversation • Difficulty reading social cues/body language • Inappropriate timing
Motor Speech/Voice Deficits	------- (3)	• Difficulty with speaking • Embarrassment with how they sound • Swallowing issues that cause garbled speech
Nonspecific	------- (2)	• Some have problems communicating with others • Lack of common sense

*number of comments which fit into the correlating category

**this comment does not directly describe a communication difficulty, but it does suggest underlying information processing deficits that would necessitate such caregiver actions and so it was categorized accordingly

There were a total of 41 comments related to the communication difficulties of individuals with TBI provided by the participants of this survey. Each comment was included, even when similar comments were mentioned by multiple people. The categories under which the comments were made most often by the respondents included “Verbal Expression” with a total of nine comments, “Pragmatics/Social Communication” with a total of seven comments, and “Memory and Learning” with a total of five comments. Every other category had no more than three total comments. Participants varied by how many pieces of insight they chose to provide. Three of the 12 participants only mentioned one communication difficulty of people with TBI each. The participant who provided the most insight made a total of nine comments about different difficulties. The rest of the participants

fell somewhere within the range of one to nine comments. Two participants made two comments each, one participant made three comments, four participants made four comments each, and the remaining participant made six comments. The comments also varied based on how insightful they seemed. For example the two comments which were categorized as "Nonspecific" fit that label because they were vague or did not describe an actual communication difficulty. The comments in that category were "some have problems communicating with others" and "lack of common sense". The "lack of common sense" comment does not show insight into the underlying impaired cognitive processes that could suggest this participants' evaluation of the individual with TBI. On the other hand some comments were very insightful and even showed the respondents understanding of how communication difficulties affect the feelings of individuals with TBI. For example, the comment that "repetition in conversation embarrasses the person with TBI" shows that the caregiver not only understands that repetition in conversation is a communication difficulty for the person with TBI with whom they work, but also insight into the feelings of the person that this particular difficulty causes them to be embarrassed.

Strategies in Communication

After identifying communication difficulties that individuals with TBI might experience the survey participants were asked to comment on strategies that they use to help overcome communication difficulties. All 12 participants who reached this point in the survey provided a response to this question. In table 5 below the researcher has paraphrased the responses and categorized them based on the type of strategy. Some participants' individual responses fit nicely into one category, while others were divided into different categories in order to best describe every strategy suggested. The four categories that

described the strategies were as follows: “Caregiver Behavior”, “Support for Person with TBI’s Behavior”, “Manipulation of Environment”, and “Utilization of External Resources”. Please see table 5 below for a list of each paraphrased strategy in their corresponding categories.

Table 5: Strategies

Category	Strategy
Caregiver Behavior	Slow down and thoroughly explain the situation and ask for clarification to make sure they are processing the information.
	Do not interpret or finish their sentences.
	Provide friendly reminders of social norms and common cues.
	Choose between open ended and yes/no questions.
	Rephrase if the person is having difficulty understanding.
	Model good conversation skills.
	Provide direct feedback on impulsive comments.
	Clearly identify goals and use of good time management.
	Monitor the individual’s level of agitation in order to prevent anxiety and redirect them to a comfortable subject to reduce anxiety and the amount of information being processed.
	Include them in activities and exercise both physically and mentally.
Support for Person with TBI’s Behavior	Ask them to repeat themselves when needed.
	Give the person adequate time to express themselves and try not to rush them.
	Tell them to slow down and take their time.
	Wait and give the person time to respond.
	Provide verbal cues for word finding.
	Use non-verbal cues.
	Ask them to explain what they may be talking about.
	The person with TBI must keep their own notes to remain as organized as possible in order to reduce anxiety, remember important information, and prevent seizure activity.
Manipulation of Environment	Try to keep the person in conversation and around others he is comfortable with so he will just keep talking and they won’t correct him.

	Look the person in the eye and get on their level physically.
	Take the person to a quieter and more private place for a conversation to reduce distractions and allow them privacy for freedom to express themselves.
Utilization of External Resources	Practice social interactions through social stories.
	Use journals and lists.
	Send an email following a formal assessment to summarize the conversation and highlight what the person with TBI should be working on versus what I (the caregiver) should be working on.

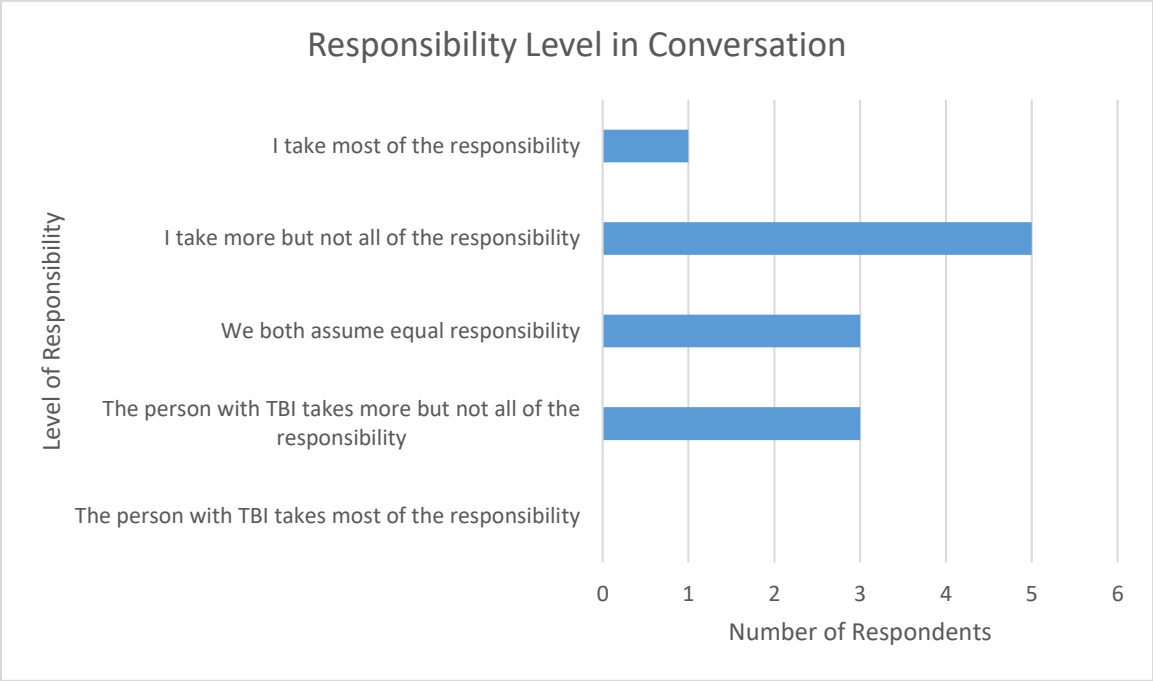
The category that had the most strategies was the one for "Caregiver Behavior" with a total of 10 strategies. It was followed by "Support for Person with TBI's Behavior" with eight strategies. The categories of "Manipulation of Environment" and "Utilization of External Resources" had the same number of strategies with three each. Some basic suggestions were mentioned by multiple participants, so some of the strategies in the table above are very similar to others. For example, three different participants mentioned the strategy of allowing the person with TBI an adequate amount of time to comprehend the conversation and respond.

Structure of Conversational Interaction

One of the purposes of this study was to assess the nature of the caregivers' interactions with people with TBI. The first question seeking this information asked the caregivers "Who takes more responsibility in conversations? (who starts a conversation, adds new information, asks more questions)?". Participants were then able to choose from the following series of responses: "I take most of the responsibility", "I take more but not all of the responsibility", "We both assume equal responsibility", "The person with TBI takes more but not all of the responsibility", and "The person with TBI takes most of the responsibility".

Twelve participants responded to this question, and five of them chose the options that they "take more but not all of the responsibility". Three participants put themselves in the category for assuming equal responsibility, while another three said that "the person with TBI takes more but not all of the responsibility". The remaining respondent said that they "take most of the responsibility". No participants selected the category that indicated "the person with TBI takes most of the responsibility".

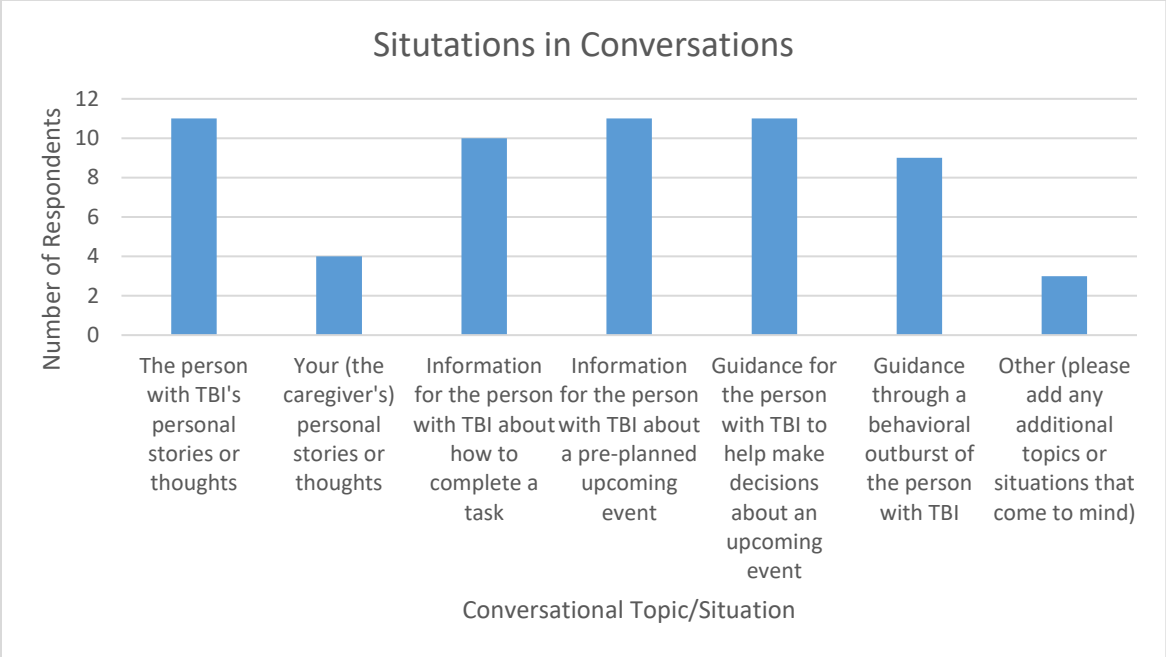
Figure 5: Responsibility Level



The participants were also asked which topics or situations were often discussed in conversations with individuals with TBI. They were instructed to choose as many topics as applied and were given the following choices: "the person with TBI's personal stories or thoughts", "your (the caregiver's) personal stories or thoughts", "information for the person with TBI about how to complete a task", "information for the person with TBI about a pre-planned upcoming event", "guidance for the person with TBI to help make decisions about

an upcoming event", "guidance through a behavioral outburst of the person with TBI", and "other (please add any additional topics or situations that come to mind"). There were three categories which tied for the most often selected with 11 participants selecting each category. These categories included "the person with TBI's personal stories or thoughts", "information for the person with TBI about a pre-planned upcoming event", and "guidance for the person with TBI to help make decisions about an upcoming event". A close second in terms of number of responses was the category of "information for the person with TBI about how to complete a task" with nine respondents choosing this category. Eight respondents said that "guidance through a behavioral outburst of the person with TBI" is part of their conversations. Only four participants said that they shared their own "personal stories and thoughts" and three participants chose to specify a different category by choosing the "other" option. The three categories that were added by participants were to "try to help him with his [sic] why his daughter might not be calling him as much as she use [sic] to", "general problem solving", and "individuals repeat information several times and though [sic] repetition the individuals are able to gain confidence in their recall of information".

Figure 6: Conversational Situations



Attitudes

Attitudes of the caregivers toward conversational interactions were also assessed as part of this study. The researcher asked participants "Do you sometimes feel frustrated when having a conversation with a person with TBI?" in a yes/no response format. This question was answered by all 13 participants, nine of which answered "no" while only four responded "yes" that they were sometimes frustrated. The four participants who responded positively to the question were then asked if they could identify some sources of their frustration in an open response format. The respondents not only stated the behavior or attributes of conversing with a person with TBI that sometimes frustrate them, but also provided some insight into their own feelings. The only attribute of individuals with TBI that was mentioned by two participants as a source of frustration was issues with memory. See table 6

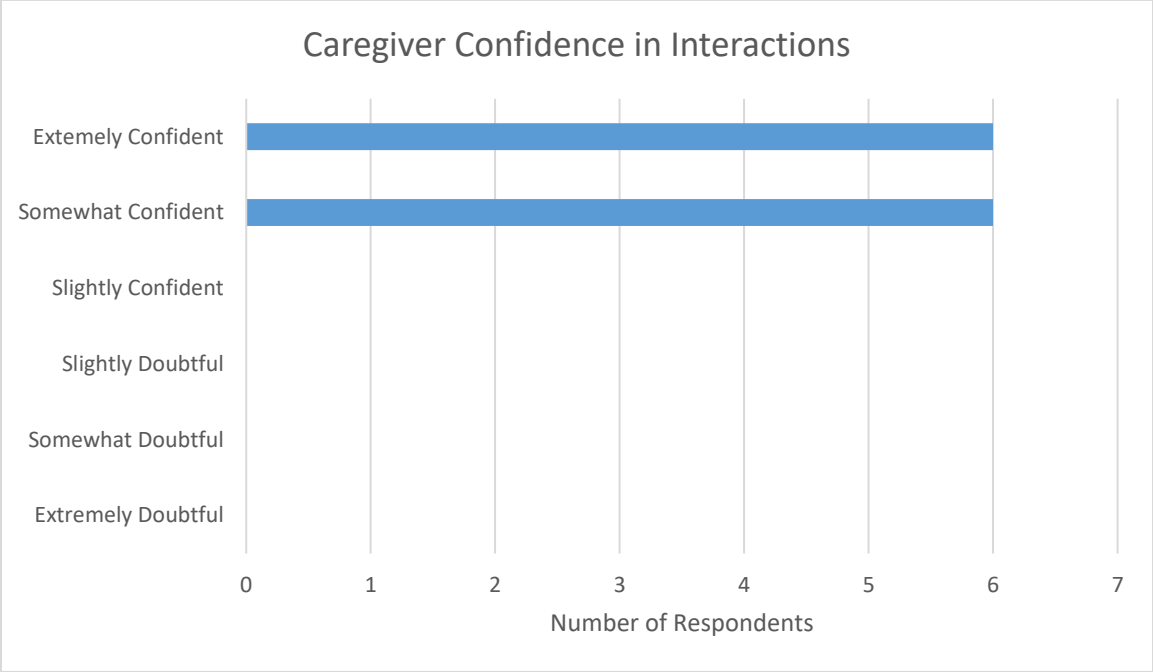
below for a summary of each participant's analysis of their occasional frustrations when conversing with individuals with TBI.

Table 6: Caregivers' Frustrations

Behavior of the Person with TBI	Feelings of the Caregiver
He remembers some things and some things he doesn't remember	Wonders sometimes if he fakes some of it his issues with memory
Memory issues	-----
Cannot help the situation because of problems with aphasia, mentally processing questions and answers, not liking to speak because of not liking the sound of their own voice or not liking to speak because people ask them to repeat themselves so often	Does not show frustration because they realize the person with TBI cannot help the situation because of the issues listed to the left
------	Feels frustrated when there is something they cannot help the person with or when they are in the middle of something and need to stop and change the direction of their attention

The researcher also tried to gauge the caregivers' feelings about their own role in conversations with individuals with TBI. The survey participants were asked the questions "How confident are you in your current ability to communicate effectively with individuals with TBI?" and then given a range of answers to choose from. Possible answers were as follows: "extremely confident", "somewhat confident", "slightly confident", "slightly doubtful", "somewhat doubtful", and "extremely doubtful". Of the 12 respondents six stated that they were "extremely confident", while the other 6 chose the option of "somewhat confident". No one selected any of the other categories.

Figure 7: Caregiver Confidence

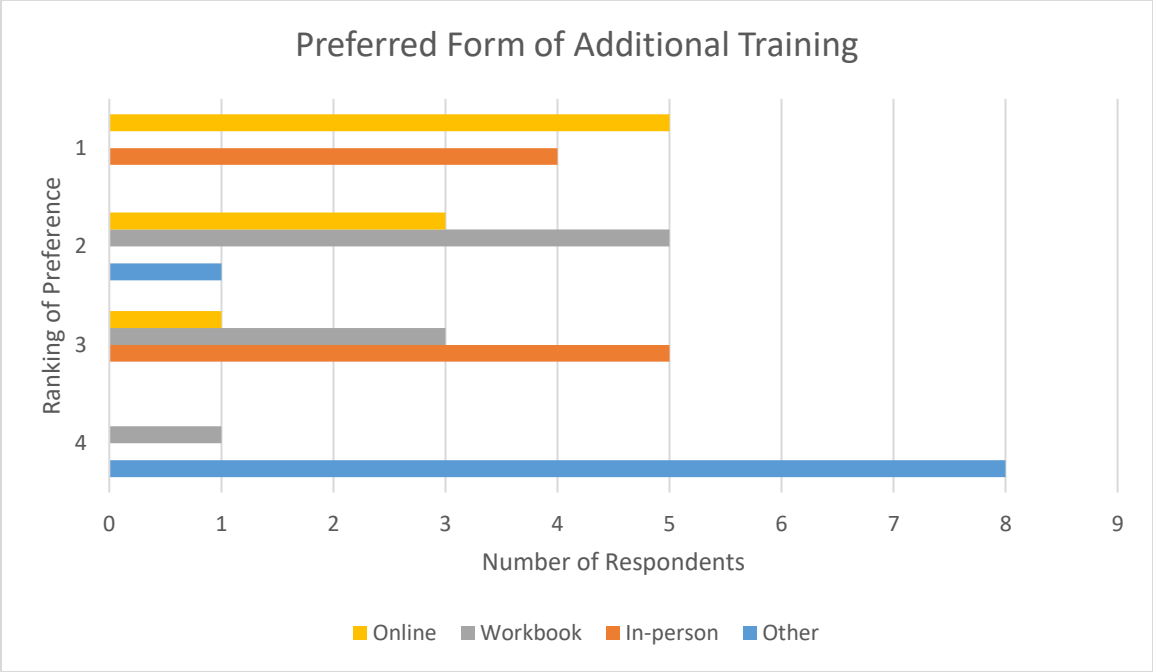


Additional Training

One of the last questions asked as part of the survey once the participants had had the opportunity to reflect on their knowledge of and interactions with people with TBI was "would you like more training on communicating with individuals with TBI?". This question was displayed to 12 participants, nine of which indicated that they would like more training by choosing "yes" while the remaining three said "no" they would not like more training. The nine participants who answered that they would like more training were then asked to rank which forms of training they would prefer. They were given the options of an "online course", "workbook", "in-person seminar", and "other (please specify)" and then asked to rank them from "1" to "4" with "1" being the most preferred and "4" being the least preferred. Four of the nine individuals who answered this question didn't move any of the options around in the answer section and therefore there were no ranking numbers by their

choices. However, the researcher assumed that their lack of manipulation of the answer was due to the fact that the choices were already in the order that they preferred and so their responses were still included in the data. The two forms of training that were ranked as most preferred or "1" were "online" training with five respondents choosing this option and an "in-person seminar" with four responses in favor. The form most often ranked as second was a "workbook" with five respondents, followed by "online" training with three respondents and finally "other" was chosen by one respondent as their second option. This person chose to specify their idea of an additional "other" training form as "one on one training with a trainer and individuals with TDI [sic] would be an ideal situation in order to understand the perspective of both a professional trainer and different individuals with TDI [sic]". Although this form is similar to the more general "in-person" training it does focus more on training a professional to interact with one individual specifically than any of the other options allow. The "in-person seminar" option was most frequently ranked as third with a total of five respondents in support. Three respondents chose "workbook" as their third preference, and only one respondent ranked "online" training in this category. Finally, most of the respondents chose the "other" option as their fourth choice and did not specify any other sort of training. Eight of the nine participants were included in that group, while the remaining one participant specified the "workbook" option as their least preferred form of training.

Figure 8: Additional Training Preferences



Other Information

The last question of the survey was optional and asked participants to "Please add any additional information related to communicating with individuals with TBI" that they would like to share. Only 4 of the 12 participants chose to respond. Two individuals chose to provide more tips for how to interact with people with TBI both generally and in the specific role of a caregiver. Another participant simply posted links to websites that offer training on interacting with the TBI population. Content from 3 of the 4 websites that were mentioned was reviewed as training sources in the literature review portion of this study. The final respondent provided some general insight into how variable difficulties that accompany a TBI can be from individual to individual and noted the benefit of having experience interacting with other special populations. Please see table 7 below for their individual comments.

Table 7: Additional Comments

Making them feel comfortable.
One of the most common problems that new caregivers have is not allowing the individual time enough to process what they have said and not giving them time to answer. I have learned that it is very important to begin relationships with Survivors using a low, calm voice rather than a loud voice. Sometimes hearing issues do not allow this however.
http://sydney.edu.au/health-sciences/tbi-express/ www.brainline.org www.nctbitraining.org www.msktc.org
The range of disabilities that occur along with a primary TBI diagnosis are wide ranging and an understanding of strategies needed to work and communicate with other I/DD diagnosis is extremely useful.

Discussion

Participants

Some of the demographic information gathered in this study was comparable to that found in other studies that have also gathered demographic information of paid caregivers (Behn et al., 2012; McCluskey, 2000). The only two categories from both studies that can be compared directly to results found in this study were those of gender and age. In the McCluskey (2000) study, 4 of the 5 caregivers were female while all 10 of the caregivers in

the Behn et al. (2012) study were female. These results line up well with the findings from this study where 12 of the 13 caregivers were female and support the idea that caregiving of individuals with TBI is primarily a female dominated career. All five caregivers from the McCluskey (2000) study were 37 years old or younger which correlates well with the present study as the largest cohort of participants, with 7 of the 13 total participants, identified themselves as 37 years old or younger. The Behn et al. (2012) study had a slightly larger proportion of younger participants in their sample population with 7 of the 10 participants being either 29 years old or younger. However the remaining three participants in the Behn et al. (2012) study were 46 years old or older which is similar to the age range of 48 years or older that the remaining six participants of the present study belonged to. It is interesting to note that in all three studies no participants fell within the range of 38-45 years old (Behn et al., 2012; McCluskey, 2000). From these results it appears that there is a slightly larger proportion of younger caregivers under the age of 37 within the field than those in their late 40s and beyond, but the number of participants in each of the studies looked at are so low that no conclusions can really be drawn about the common ages of professional caregivers of individuals with TBI based solely on their results.

Years of employment in the caregiving profession were reported differently by each study. The McCluskey (2000) study gathered data on how long the caregivers had worked with the specific person with TBI that they currently cared for, while the Behn et al. (2012) study looked at how many total years the caregivers had worked with people with acquired brain injury (ABI). In McCluskey (2000) the longest employed caregiver had been working with their individual for 5 years while the most recently employed caregiver had only been working for 9 weeks. In the Behn et al. (2012) study, 6 of the 10 participants had been

working with individuals with ABI between 3 to 3.5 years and the remaining 4 participants had all been working with the population for shorter periods of time. Many of the participants in the Behn et al. (2012) study had been working as caregivers for longer periods of time than just the time that they reported as working with individuals with ABI. However, their additional caregiving experiences were with other populations such as people with dementia, developmental disabilities, or mental health issues (Behn et al., 2012). The majority of the participants in the present study, 8 out of the 13 total, had been employed with individuals with TBI for 6 years or less. It seems that among the three studies, being employed for less than 6 years with individuals with TBI was not uncommon and may reflect high turnover rates within the field. Although, there were three respondents in the present study who had been employed with the population for over 12 years which shows that this is not always the case. The three participants in this study who had been employed for the longest period of time were also three of the oldest participants. There did not appear to be any trends such as number of individuals that they worked with, education level, or job title that would suggest their long period of employment.

Neither the McCluskey (2000) study nor the Behn et al. (2012) study looked specifically at the type of educational degrees held by the caregivers, but the Behn et al. (2012) study did gather information on number of years of education of the participants. The 10 participants in the Behn et al. (2012) study had completed education ranging from 11 to 14 years. This indicates that some of the participants did not complete high school while others had some college education (Behn et al., 2012). The information from the Behn study differs somewhat from the present study in that all of the participants of the present study had at least completed high school. Although there could be different educational requirements

between the two sample populations based off of their countries of origin. As expected, there was some correlation between level of education and job title in the present study. Four of the 6 respondents whose job titles were categorized as "Administrative Staff" held Bachelor's degrees. One of the other respondents in this category had a Master's degree while the remaining respondent in the category was the one who was a licensed practical nurse. Therefore it appears that one must hold some degree or licensure beyond high school to be in a specialized or administrative position. Many of the participants whose job titles were categorized as "Direct Support Staff" also had higher education. More specifically, two participants in this category held Bachelor's degrees and two held Master's degrees. Two other participants had completed some college courses and the remaining participant had a high school diploma or GED. This data suggests that for some direct support positions a higher education degree is not necessary, although requirements seem to be highly job specific as some participants in this category held a Master's degree.

There did not appear to be any trends between the number of individuals with TBI that caregivers in this study worked with and any other demographic information gathered. Although it was clear that fewer numbers of individuals with TBI, such as one or two each, were most common among participants. Among the options for settings where the participants of the survey worked with individuals with TBI, the person with TBI's personal residence, group home settings, and day program settings tied for being the most common with three responses each. However, perhaps more significant than the number of caregivers in each setting is the wide variety of settings where caregivers may work with individuals with TBI. This study shows that they may work in the person with TBI's personal residence, in the community, in a group home setting, in a day program setting, in the caregiver's home,

in hospitals, rehabilitation hospitals, and residential rehabilitation facilities. These results are not surprising as caregivers of individuals with TBI have been studied in rehabilitation and home health settings (Behn et al., 2012; McCluskey, 2000). The group home and day program setting were also expected as the researcher contacted these types of facilities when recruiting participants.

Many of the participants who responded to the survey were not exactly the target population the researcher had intended for the study. The researcher intended to reach individuals who were primarily in direct support positions with individuals with TBI and anticipated that they would primarily serve in group home or day program settings. The individuals who actually responded were from more specialized healthcare fields than expected, however their specific responses still provided useful data. Nevertheless, the lack of response from those in direct support positions highlights how the intended target population was difficult to reach. When recruiting participants for the survey the researcher emailed a link to contacts, many of whom were directors of programs, who were then tasked with forwarding the link to caregivers that they may know. The lack of responses from direct support staff either indicates that many of the contacts did not forward the link, or that the direct support staff were uninterested in the survey or unable to complete the survey for other reasons such as lack of access to technology.

Types of Training

According to BIAUSA (2016a) there were a total of 252 Certified Brain Injury Specialists (CBIS) in North Carolina as of August 1, 2016. Out of the 13 respondents to this survey of caregivers in North Carolina, five identified themselves as CBIS. All five of the participants who were CBIS possessed higher education degrees. All three respondents of

the survey who had Master's degrees were CBIS, as well as two participants with Bachelor's degrees. This suggests that perhaps people who have previously pursued higher education are more likely to pursue CBIS certification. The three participants who possessed Master's degrees were under the age of 37 while the two with Bachelor's degrees and CBIS certification were over the age of 48. The two older participants with Bachelor's degrees were also two of the longest employed caregivers of individuals with TBI, one for 12 years and the other for 22. This data could suggest that higher levels of education, such as Master's degrees, are becoming more important for younger incoming professionals in the field. There did not appear to be a strong association between whether the participant was a CBIS and whether their job title was categorized as "Administrative Staff" or "Direct Support Staff" as 3 of the 5 CBIS were administrative and the other 2 were direct support. Finally, all of the CBIS served more than just one or two individuals with TBI. The number of individuals they served ranged from 9 to 500.

A larger proportion of individuals who were classified as "Administrative Staff" reported that they had completed training related to communicating with individuals with TBI than those who were "Direct Support Staff". Five of the 6 "Administrative Staff" reported that they had completed this type of training, while only 3 of the 7 "Direct Support Staff" reported this type of training. Nevertheless, not all of those who responded gave much information about the training that they received nor was it clear that the training related specifically to communication. For example it is unlikely that the "Technology and TBI" training related to communication as the participant who said they had completed it stated that it was about "different software to use". Responses gathered from the question that asked about communication training as well as the question which asked about other

additional types of training, only resulted in two reports of any form of training that was covered in the literature review portion of this study. That training program was the online modules known as NC TBI (NC DHHS, n.d.-b). One participant who had earlier expressed that they had completed the NC TBI training program mentioned the online version of the TBI Express program in the additional comments section of the survey as well (Togher et al., 2012b). The same participant also mentioned other online resources regarding traumatic brain injury in the additional comments section, such as brainline.org and msktc.org, although neither of these resources were covered in the literature review section. Due to the fact that the participant provided the names of most of these resources in the additional comments section of the survey rather than under the questions that asked about trainings that had been completed, it is unclear whether the participant actually utilized these resources or was just aware of them. Other sources of training information on TBI that were mentioned by the participants included the Defense Centers of Excellence (DCoE) and the Brain Injury Association of America (BIAA). Specific forms of training completed by the participants which could have had some relation to communication skills included "person centered thinking", "motivational interviewing" and "nonviolent crisis intervention". It is clear from the participants' responses that they also found general training regarding the nature of TBI to be beneficial to their communication skills as caregivers. It is apparent that experience with other populations such as those with dementia and intellectual disabilities was perceived as beneficial by the caregivers when working with individuals with TBI as well.

Recognition of Difficulties

The only question of this survey that had a unanimous response was the one that asked if caregivers believed that people with TBI suffer socially because of their

impairments. This is significant because their positive answers show that they are aware of one of the most distressing consequences of a brain injury for survivors (Hoofien et al., 2000). It also shows that therapy that targets social functioning for people with TBI, such as training communication partners, is necessary. The caregivers' awareness of negative social aspects validates consideration of training members of this population who interact with people with TBI on such a regular basis.

The participants also reported common communication difficulties of people with TBI. The difficulties that they listed were examined based on some of the categories presented on the ASHA Practice Portal TBI page (ASHA, 2016b). All of the comments fit nicely into these categories, with the exception of the two classified as nonspecific. This indicated that most of the caregivers identified legitimate communication issues that are common for people with TBI. Their contributions were also in line with the difficulties identified in a study by Togher et al. (1999) which included issues with information processing, articulation, memory, repetition, difficulty with abstract references, attention, and other cognitive, motor and social impairments. The two categories of impairments that received the most attention by the participants were those of "Verbal Expression" with nine comments and "Pragmatics/Social Communication" with seven comments. The attention of the participants to the pragmatic and social difficulties of individuals with TBI is another indicator of their understanding of the impact that TBI can have on the social functioning of survivors. This study therefore contributes evidence that social functioning should be an area of focus for intervention for individuals with TBI through the most effective means, which should in many cases include the communication partner training model addressed in this study.

The participants who said they had previously received communication training more frequently identified more difficulties than those who had not received training. The individuals who had not received communication training were also all members of the "Direct Support Staff" group. Therefore it appeared that as a group the participants who were "Administrative Staff" were more knowledgeable about common impairments. Although a wide array of impairments were mentioned by all of the participants of the study as a group, the comprehensiveness of their individual answers were highly variable. Some participants only mentioned one impairment, while others mentioned up to nine. However, even the one participant who mentioned nine different impairments only acknowledged seven of the 12 areas of impairments discussed in this study through their response. Therefore it appears that some participants in this study could benefit from communication training more than others, although training would likely provide some new knowledge to all of the participants.

Strategies in Communication

The communication strategies provided by the survey participants were valuable in that they provided some insight into what strategies are perceived as beneficial by the sample population of caregivers. Assuming that the participants commonly use the strategies that they suggested with the individuals that they work with, their contributions also gave some insight into typical interactions. Some of the strategies that the participants suggested were similar to communication tips provided by the communication training programs that were tested in the literature, specifically the TBI Express Program (Togher, 2013; Togher et al., 2012b). The strategies that the survey participants provided were closest to the tips in the TBI Express Communication Strategies Toolkit such as using memory or organization

supports, giving information and cues when needed, taking appropriate conversation turns, and acknowledging difficulties of the person with TBI as well as communicating respect for them (Togher, 2011b). However, there were other strategies suggested by the TBI Express program that participants of the study did not identify such as showing enthusiasm for the person with TBI's contributions and creating a collaborative environment, questioning in a supportive and non-demanding manner, and encouraging elaboration of topics (Togher, 2011b). Therefore it seems as though participants of this study did well with suggesting strategies to help manage difficulties, but they did not suggest as many strategies designed to create a more positive and fulfilling communicative environment for both conversation partners.

There were a few strategies that were mentioned by the survey participants that could still provide some benefit to the individuals with TBI even though they were not explicitly covered in the communication training programs such as asking the person to repeat or explain themselves when they are not understood, providing direct feedback on impulsive comments and reminders of social norms, including the person in activities, and clearly identifying goals. Some of these strategies may not create the most natural conversational environment, but they might help with organization and social functioning in some situations.

There were only a few strategies that went directly against strategies suggested in communication training programs. These mainly included strategies related to questioning behaviors. Instead of asking true and interesting questions the participants suggested choosing between open ended and yes/no questions and asking questions to check for comprehension of the person with TBI. These behaviors could greatly restrict the amount of information the person with TBI could contribute to the conversation and create an unequal

power structure between the two participants (Mann et al., 2015). One participant also suggested practicing social interactions through social stories. This strategy is not necessarily bad, but it is contrived. More experience with true social interactions would be a more authentic form of intervention and likely be more beneficial and enjoyable for the person with TBI (Ylvisaker, 2006). The participants of this study as a group indicated that they have a good knowledge base of useful strategies, but that there is definitely room for improvement, and thus, increased training may be beneficial.

Structure of Conversational Interaction

Togher (2000) found that the power structure between two communication partners can affect how well a person with TBI performs in a conversation. When the person with TBI is given more opportunity to contribute new information to the conversation they are given the chance to take on the role of an equal conversation partner. The researcher of this study attempted to have the participants assess the power structure of the conversation by asking them "who takes more responsibility in conversations?". The person with more responsibility was described as being the person who "starts a conversation, adds new information, (and) asks more questions". The ideal response to this question that would have indicated the best possible power structure between the two conversation partners was "we both assume equal responsibility". However, this response was only chosen by 3 of the 12 respondents to the survey. Most of the participants stated that they assumed more of the responsibility of the conversation than the person with TBI. It is possible that this question could have been interpreted in different ways by different participants and it is possible that it is not a very accurate way to truly examine the power structure between two conversation partners. The ideal way to obtain this information would have been to observe and analyze

conversational interactions between conversation partners. However, the participants' responses indicate that as a group they are aware of the fact that participants in a conversation are not always equal in the interaction, and that most felt as though they assume responsibility and power in guiding conversational interactions.

The researcher also tried to gain some insight into common contexts of conversations between caregivers and individuals with TBI. The survey participants were asked to identify topics or situations that they often discussed with the individuals with TBI that they worked with. The researcher provided an array choices for the participants to choose as responses which included situations that were intended to reflect both unstructured and structured conversations. The options of "the person with TBI's personal stories or thoughts" and "your (the caregiver's) personal stories or thoughts" were the two choices intended to reflect unstructured conversations. Three participants chose to add additional topics or situations that didn't fit into the set choices that were provided and one of their additional comments fit under the unstructured conversation category which was, "try to help him with his [sic] why his daughter might not be calling him as much as she use [sic] to". The participants were able to specify as many conversational categories as they deemed relevant in their relationships. As a group the participants only chose unstructured situations 16 times, while they chose the structured situations 46 times. It therefore seems as though structured conversations are more common in the relationships of people with TBI and their employed caregivers than unstructured conversations. However it cannot be determined from the data which contexts occur most often in conversations, but rather which forms occur for more people. Although, the fact that there were many more options of structured forms could also have skewed the data in that direction. Regardless, it seems logical that more structured

forms of conversation would be more common in this type of professional relationship. A study by Behn et al. (2012) trained paid caregivers on communication techniques and found that the caregivers showed more improvement in structured conversations than unstructured after training. The researchers hypothesized that the difference was related to a higher frequency of structured interactions in their conversations with individuals with TBI (Behn et al., 2012). It is important to consider which contexts of conversation are more common in the professional interactions of caregivers in order to determine which areas of communication training should focus on in order to provide maximum benefit to both the caregiver and the individual with TBI.

Attitudes

The participants of this study were asked to identify some sources of potential frustrations in conversations with individuals with TBI. Only four participants admitted that they ever felt frustrated when having conversations. Of the four participants who responded to this question, two mentioned issues with memory as their main sources of frustration. Memory was the third most mentioned category of impairments when all of the participants were asked to identify communication difficulties of individuals with TBI earlier in the survey. There were no new categories of impairments mentioned as a result of the question that prompted frustrations. Instead this question provided more insight into the caregivers' feelings. The caregivers who did admit occasional frustrations in their conversations still showed empathy for the person with TBI and an understanding of issues beyond their control. Their perceptions show that they are aware that the person with TBI cannot just stop having difficulties with communication, which provides further evidence for an approach to

intervention that does not focus on the person with TBI such as communication partner training.

Additional Training

Only 12 of the 13 study participants reached the point in the survey where they were asked if they would like additional training on communicating with individuals with TBI. Of those 12 participants, nine answered that yes they would like more training. All three of the respondents who stated that they would not like more communication training had stated earlier in the survey that they had not previously completed training related to communication. Only one of the participants who earlier said that they had not completed any such training stated that they would appreciate additional communication training, while the other participant who responded with a "no" to the original communication training question exited the survey before reaching the question that asked about additional training. From these results it appears that those who have already completed communication training are more open to additional training of that sort, while some who haven't had such training have no desire to complete it. The three participants who said they would not like more training were all also in "Direct Support Staff" roles. The trend that these findings suggest that those who have not received communication training and are in direct support roles with individuals with TBI are not as open to training regarding communication, is somewhat disappointing as it is likely that this is the very population that would benefit most from such training. Although, perhaps more incentives for completing additional training such as compensated time would increase their willingness. If these caregivers are expected to complete supplementary trainings on their own time or for minimal pay it is not surprising that they would not be willing to take on the additional burden.

It would appear from the results that online training is the most frequently desired form of training by the participants, however these results may be skewed by those who didn't move around the options for training when they responded to the question. It was assumed that they left the options as they were because they were the in the order that they preferred, but it is possible that they did not understand how to respond to the question in that format. This is especially suspicious as 3 of the 4 participants who responded in this way were also the three oldest participants of the study. It seems odd that the older participants would prefer online training over the younger participants who have likely had more experience with technology of that sort over their lifespan and career. Therefore, it seems more likely that the older users did not understand the format of the question. When the responses of those who did not manipulate the answers are removed from the data, the preferred forms of training shift. It becomes clear that among the rest of the participants, in-person seminars are the most preferred followed by online training and ending with workbooks as the least preferred. These results seem more logical as it is likely that in-person seminars and online trainings are the forms of training that this population has previously completed. In-person training is also the form of communication training with conversation partners that has been tested in the literature (Behn et al., 2012; Togher et al., 2004; Togher et al., 2013). It has proven to be beneficial and would probably be the best form of training for this population. There are also current forms of online training available and it appears that some of the participants have utilized these resources as well (Togher et al., 2012b; NC DHHS, n.d.-b). Therefore the results of this survey show that the current forms of training are those most desired, and that providing an in-person seminar on how to

communicate with individuals with TBI would be welcomed by most participants of the survey who desire such training.

Limitations and Future Directions

One of the most prevalent limitations of this study was the small number of participants. The low response rate necessitated the use of a descriptive qualitative approach over statistical analysis. Therefore there was no opportunity to identify any widespread trends in the data that may have been present with more participants. Nevertheless, the qualitative approach did allow for a more in depth description of the results than a statistical analysis would. Furthermore results cannot truly be generalized to all caregivers in North Carolina as the small sample population may not have been representative of all caregivers. It became apparent as the researcher attempted to recruit participants for the survey that it was very difficult to reach the target population of professionals who were providing direct care to individuals with TBI. There could have been multiple reasons for the lack of response by these direct care professionals including not receiving the email survey link to begin with, not having access to technology to complete the online survey, or perhaps just not being interested in or seeing the value of the research. Regardless of the reason for limited responses, it appears that further support of research by employers of caregivers to encourage their employees' participation is necessary for the success of studies such as this one.

The present study tested caregivers' knowledge of working with individuals with TBI, rather than their skill. Participants were asked to report on areas such as strategies that they use to overcome communication difficulties that individuals with TBI may have and their responses indicated that they have knowledge of useful strategies. However, the

frequency that these strategies are used in real conversations cannot be determined by the survey format of this study. That would require observation and analysis of caregivers in their everyday environment with individuals with TBI. In the future that careful, realistic observation of numerous caregivers would be necessary to truly determine if current levels of communication training are adequate in North Carolina.

Other Considerations

Instead of just asking participants to identify communication difficulties of individuals with TBI, the researcher could have also asked the caregivers what they perceived to be the individuals' communication strengths. This would have given more insight into the perceptions of people who are with members of the TBI population on a regular basis. Responses to the question would have shown whether the caregivers understand that individuals with TBI do still have strengths and possibly could have prompted caregivers to provide strategies they use regarding those particular strengths. It also could have represented people with TBI in a more positive light throughout the study and drawn attention to some of their positive and unique abilities rather than just common impairments.

References

American Speech-Language-Hearing Association [ASHA] (2016a). Traumatic brain injury in adults: Roles and responsibilities. *American Speech-Language-Hearing Association.* Retrieved from http://www.asha.org/PRPSpecificTopic.aspx?folderid=8589935337&section=Roles_and_Responsibilities.

American Speech-Language-Hearing Association [ASHA] (2016b). Traumatic brain injury in adults: Signs and symptoms. *American Speech-Language-Hearing Association.* Retrieved from http://www.asha.org/PRPSpecificTopic.aspx?folderid=8589935337&section=Signs_and_Symptoms.

Behn, N., Togher, L., & Power, E. (2015). Experiences from a communication training programme of paid carers in a residential rehabilitation centre for people with traumatic brain injury. *Brain Injury*, 29(13-14), 1554-1560.

Behn, N., Togher, L., Power, E., & Heard, R. (2012). Evaluating communication training for paid carers of people with traumatic brain injury. *Brain Injury*, 26(13-14), 1702-1715.

Brain Injury Association of America [BIAUSA] (2016a). Academy of certified brain injury specialists: Current certificants. *Brain Injury Association of America.* Retrieved from http://www.biausa.org/acbis.

Brain Injury Association of America [BIAUSA] (2016b). Welcome to ACBIS!. *Brain Injury Association of America.* Retrieved from http://www.biausa.org/acbis.

Brain Injury Association of North Carolina [BIANC] (2016). Education and training. *Brain Injury Association of North Carolina.* Retrieved from http://www.bianc.net/help/training.

Centers for Disease Control and Prevention [CDC] (2016a). Rates of TBI-related emergency department visits, hospitalization, and deaths – United States 2001-2010. *Centers for Disease Control and Prevention.* Retrieved from https://www.cdc.gov/traumaticbraininjury/data/rates.html.

Centers for Disease Control and Prevention [CDC] (2016b). TBI: Get the facts. *Centers for Disease Control and Prevention.* Retrieved from https://www.cdc.gov/traumaticbraininjury/get_the_facts.html.

Constantinidou, F. & Kennedy, M. (2016). Traumatic brain injury in adults. In I. Papathanasiou, & P. Coppens (Eds.), *Aphasia and related neurogenic communication disorders (2nd Ed)* (pp. 421-454). Burlington, MA: Jones & Bartlett Learning.

Ducharme, J.M. & Spencer, T.F. (2001). Training brain injury rehabilitation therapists to use generalized teaching and interaction skills. *Brain Injury*, 15(4), 333-347.

Friedland, D. & Miller, N. (1998). Conversation analysis of communication breakdown after closed head injury. *Brain Injury*, 12(1), 1-14.

Hoofien, D., Gilboa, A., Vakil, E., & Donovick, P.J. (2001). Traumatic brain injury (TBI) 10-20 years later: A comprehensive outcome study of psychiatric symptomatology, cognitive abilities and psychosocial functioning. *Brain Injury*, 15(3), 189-209.

Hooper, S.R., Ornitz, C., White, J.K., Lash, M., Newlin, E., Makor, L., & Farmer, S. (2015). Traumatic brain injury in North Carolina: The state of the state today. *North Carolina Medical Journal*, 76(2), 84-88.

Keegan, L.C. (2012). Review of research methods in communication disorders. *Contemporary Issues in Communication Science and Disorders,* 39, 98-104.

Mann, K., Power, E., Barnes, S., & Togher, L. (2015). Questioning in conversations before and after communication partner training for individuals with traumatic brain injury. *Aphasiology*, 29(9), 1082-1109.

McCluskey, A. (2000). Paid attendant carers hold important and unexpected roles which contribute to the lives of people with brain injury. *Brain Injury*, 14(11), 943-957.

National Joint Committee for the Communication Needs of Persons with Severe Disabilities [NJC] (n.d.). Communication bill of rights. *American Speech-Language-Hearing Association.* Retrieved from http://www.asha.org/uploadedFiles/NJC-Communication-Bill-Rights.pdf.

North Carolina Department of Health and Human Services [NC DHHS] (n.d.-a). Traumatic brain injury. *North Carolina Department of Health and Human Services.* Retrieved from https://www.ncdhhs.gov/assistance/disability-services/traumatic-brain-injury.

North Carolina Department of Health and Human Services [NC DHHS] (n.d.-b). Traumatic brain injury & public services in North Carolina: Online training. *North Carolina Department of Health and Human Services.* Retrieved from https://www.nctbitraining.org/Default.aspx.

Sack, S.H. & McLean, L.K. (1997). Training communication partners: The new challenge for communication disorders professionals supporting persons with severe disabilities. *Focus on Autism and Other Developmental Disabilities*, 12(3), 151-158.

Shepherd Center (2017). Understanding brain injury: What you should know about brain injury and recovery. *Shepherd Center*. Retrieved from http://www.braininjury101.org/.

Sim, P., Power, E., & Togher, L. (2013). Describing conversations between individuals with traumatic brain injury (TBI) and communication partners following communication partner training: using exchange structure analysis. *Brain Injury*, 27(6), 717-742.

Togher, L. (2000). Giving information: The importance of context on communicative opportunity for people with traumatic brain injury. *Aphasiology*, 14(4), 365-390.

Togher, L. (2010). Training everyday communication partners for individuals with traumatic brain injury: The influence of Mark Ylvisaker. *Seminars in Speech and Language*, 31(3), 139-144.

Togher, L. (2011a). Collaboration do's and don'ts. The University of Sydney. Retrieved from http://sydney.edu.au/health-sciences/tbi-express/resources.shtml.

Togher, L. (2011b). Communication strategies toolkit. The University of Sydney. Retrieved from http://sydney.edu.au/health-sciences/tbi-express/resources.shtml.

Togher, L. (2011c). Elaboration do's and don'ts. The University of Sydney. Retrieved from http://sydney.edu.au/health-sciences/tbi-express/resources.shtml.

Togher, L. (2013). Improving communication for people with brain injury in the 21st century: The value of collaboration. *Brain Impairment,* 14(1), 130-138.

Togher, L., Hand, L., & Code, C. (1996). A new perspective on the relationship between communication impairment and disempowerment following head injury in information exchanges. *Disability and Rehabilitation,* 18(11), 559-566.

Togher, L., Hand, L., & Code, C. (1997). Analysing discourse in the traumatic brain injury population: Telephone interactions with different communication partners. *Brain Injury,* 11(3), 169-189.

Togher, L., McDonald, S., & Code, C. (1999). Communication problems following traumatic brain injury. In McDonald, S., Togher, L., & Code, C. (Eds.), *Communication disorders following traumatic brain injury,* (pp. 1-18). East Sussex, UK: Psychology Press Ltd.

Togher, L., McDonald, S., Code, C., & Grant, S. (2004). Training communication partners of people with traumatic brain injury: A randomized controlled trial. *Aphasiology,* 18(4), 313-335.

Togher, L., McDonald, S., Tate, R., Power, E., & Rietdijk, R. (2009). Training communication partners of people with traumatic brain injury: Reporting the protocol for a clinical trial. *Brain Impairment,* 10(2), 188-204.

Togher, L., McDonald, S., Tate, R., Power, E., & Rietdijk, R. (2013). Training communication partners of people with severe traumatic brain injury improves everyday conversations: A multicenter single blind clinical trial. *Journal of Rehabilitation Medicine,* 45, 637-645.

Togher, L., McDonald, S., Tate, R., Rietdijk, R., & Power, E. (2016). The effectiveness of social communication partner training for adults with severe chronic TBI and their families using a measure of perceived communication ability. *NeuroRehabilitation,* 38, 243-255.

Togher, L., McDonald, S., Tate, R., Power, E., Ylvisaker, M., & Rietdijk, R. (2012b). TBI express partner training. *The University of Sydney*. Retrieved from http://sydney.edu.au/health-sciences/tbi-express/index.shtml.

Togher, L., & Power, E. (2010). Communication training programs for public agencies and everyday communication partners: An overview. *Asia Pacific Journal of Speech, Language, and Hearing,* 13(1), 13-19.

Togher, L., Power, E., McDonald, S., Tate, R., & Rietdijk, R. (2010b). TBI express: A communication training program for everyday communication partners of people with TBI. *ACQuiring knowledge in speech, language and hearing,* 12(2), 82-84.

Togher, L., Power, E., Rietdijk, R., McDonald, S., & Tate, R. (2012a). An exploration of participant experience of a communication training program for people with traumatic brain injury and their communication partners. *Disability and Rehabilitation,* 34(18), 1562-1574.

Togher, L., Power, E., Tate, R., McDonald, S., & Rietdijk, R. (2010a). Measuring the social interactions of people with traumatic brain injury and their communication partners: The adapted Kagan scales. *Aphasiology,* 24(6-8), 914-927.

Togher, L., Taylor, C., Aird, V., & Grant, S. (2006). The impact of varied speaker role and communication partner on the communicative interactions of a person with traumatic brain injury: A single case study using systemic functional linguistics. *Brain Impairment*, 7(3), 190-201.

Tu, L.V., Togher, L., & Power, E. (2011). The impact of communication partner and discourse task on a person with traumatic brain injury: The use of multiple perspectives. *Brain Injury*, 25(6), 560-580.

Wiltshire, G. & Ehrlich, C. (2014). Is conversation partner training effective in assisting individuals with a traumatic brain injury to display improved communication outcomes. *Journal of Social Inclusion*, 5(2), 9-26.

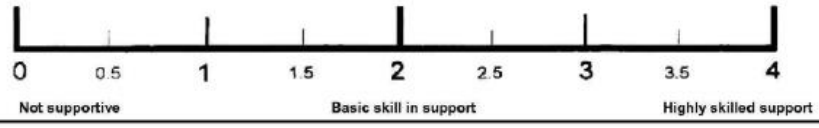
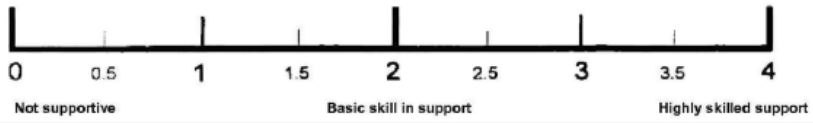
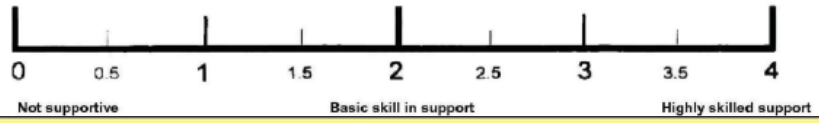
Ylvisaker, M. (2006). Self-coaching: A context-sensitive, person-centred approach to social communication after traumatic brain injury. *Brain Impairment*, 7(3), 246-258.

Appendices

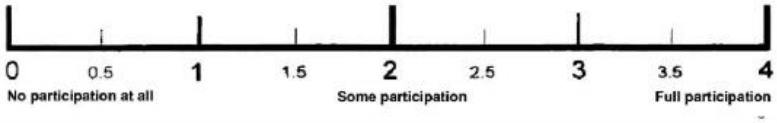
Appendix A: Adapted MPC and MSC Scales

A. Acknowledging Competence	
Natural adult talk appropriate to context	• Feel and flow of natural adult conversation appropriate to context, ○ e.g., social chat vs. interview; respectful approach to verification (verifying that the conversation partner has understood rather than verifying that adult with brain injury knows what they want to say; not over-verifying) • Not patronizing (loudness, tone of voice, rate, enunciation) • Appropriate emotional tone / use of humour • Uses collaborative talk (rather than teaching / testing) • Establishes equal leadership roles in the conversation • Uses true questions rather than testing questions
Sensitivity to partner	• Incorrect / unclear responses handled respectfully by giving correct information in a non-punitive manner • Sensitive to TBI's attempts to engage in conversation, Confirms partner's contribution. • Encourage when appropriate, Shows enthusiasm for partner's contribution. • Acknowledge competence when adult with brain injury is frustrated e.g., "I know you know what you want to say.", Acknowledges difficulties. • "Listening attitude", Demonstrates active listening (e.g. acknowledging, back-channelling) • Takes on communicative burden as appropriate / making adult with brain injury feel comfortable • Communicates respect for other person's concerns, perspectives and abilities • Questions in a non-demanding, supportive manner • Takes appropriate conversational turns
Score MSC Acknow *Comp:*	

A. Acknowledging Competence Anchors		
NONE	0	Competence of person with TBI **not acknowledged**. Patronising.
	1	**Minimally acknowledges** competence of person with TBI.
BASIC	2	Basic level of skill. **Some acknowledgement** of the competence of person with TBI.
	3	**Mostly acknowledges** the competence of person with TBI.
HIGHLY	4	Interactionally outstanding. **Full acknowledgement** of the competence of the person with TBI.

B. Revealing Competence	
1. Ensure adult understands (e.g. topic, questions)	• Verbal (e.g. short, simple sentences; redundancy; is there some verbal adaptation?) • Nonverbal ○ Gesture — Meaningful; slightly exaggerated; used to emphasize or clarify ○ Writing — Clear and visible; appropriate key words ○ Resources — Used only when necessary (would something simpler suffice?) • Response to communicative cues (e.g., reacting to facial expressions indicating confusion?) • Gives cues in a conversational manner • Provides an appropriate level of cognitive support (e.g. referring to diary, making notes) • Organises information in the conversation as clearly as possible to support comprehension (e.g., sequential order, causality, similarity and difference, association) • Makes connections between topics, reviews organisation of information (e.g. summarises)
Score MSC ***Reveal Comp 1:***	
2. Ensure adult has means of responding *(and elaborating)*	• Response to communicative cues (e.g., giving enough time to respond) • Establishes equal leadership roles in the conversation • Introduces and initiates topic of interest • Allows partner to take appropriate conversational turns • Maintains the topic by adding information • Invites elaboration (e.g. uses open-ended questions, statements, links to experiences of TBI) • Uses questions appropriate to person's ability (e.g. simple or closed questions when necessary) • Helps partner express thoughts when struggle occurs
Score MSC ***Reveal Comp 2:***	
3. Verification (Accuracy of adult's response not assumed)	• Response to communicative cues (e.g. infers intended message of the person with brain injury, based on all available cues) • Confirms understanding of what has been said (paraphrasing, checking) • Uses clarifying questions as appropriate • *Note:* Verification often involves checking in a different way (e.g., using a yes/no question)
Score MSC ***Reveal Comp 3:***	

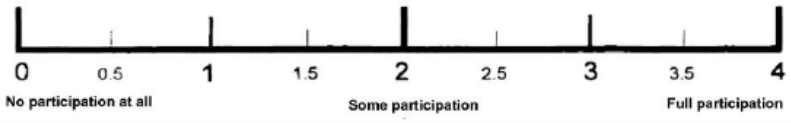
B. Revealing Competence Anchors		
NONE	0	**No use of techniques** to reveal competence. **Inhibits the potential participation** of the person with TBI.
	1	**Low level of skill** in revealing competence. **Minimises the potential participation** of the person with TBI.
SOME	2	**Basic level of skill**. Uses techniques to **maintain the potential participation** of the person with TBI. Able to get some information from the person with TBI.
	3	**Uses techniques to promote the potential participation** of the person with TBI.
FULL	4	Technically outstanding. **Uses techniques to maximise the potential participation** of the person with TBI. May not always succeed, but applies techniques flexibly and in a sophisticated way.

A. Interaction	
Verbal / vocal	• Does TBI share responsibility for maintaining feel/flow of conversation (incl: appropriate affect)? • Does TBI add information to maintain the topic? • Does TBI ask questions of ECP which follow-up on the topic? • Does TBI use appropriate turn-taking (taking their turn, passing turn to ECP appropriately)? • Does TBI demonstrate active listening (e.g. acknowledging, backchannelling)? • Does TBI choose appropriate topics and questions for the context? • Does TBI show communicative intent even if content is poor?
Nonverbal	• Does TBI initiate / maintain interaction with CP or make use of supports offered by CP to initiate / maintain interaction? • Is TBI pragmatically appropriate? • Does TBI ever acknowledge the frustration of the CP or acknowledge their competence/skill? • Behaviours might include: ○ Appropriate eye contact, use of gesture, body posture and facial expression, use of writing or drawing in any form, use of resource material
Score MPC *Interaction*:	

A. Interaction Anchors		
NONE	0	**No participation at all**. No attempt to engage with communication partner or respond to their interactional attempts.
	1	Person with TBI beginning to take **occasional responsibility for sharing the conversational interaction**, in order to achieve the purpose of the task.
SOME	2	Person with TBI making **clear attempts to share the conversational interaction some of the time**, in order to achieve the purpose of the task.
	3	Person with TBI **taking increased responsibility most of the time** for sharing the conversational interaction, in order to achieve the purpose of the task.
FULL	4	Person with TBI has **full and appropriate participation**. Takes responsibility for sharing the conversational interaction, in order to achieve the purpose of the task.

B. Transaction	

Verbal / vocal and Nonverbal	• Does TBI maintain exchange of information, opinions and feelings with CP, by sharing details or by inviting CP to share details? (i.e. is there good content and more than intent alone)?
	• Does TBI present information in an organised way?
	• Does TBI provide an appropriate amount of information?
	• Does TBI ask clarifying questions when necessary?
	• Does TBI ever initiate transaction?
	  ◦ Introducing or referring back to a previous topic
	  ◦ Spontaneously using a compensatory technique
	• Does content of transaction appear to be accurate? (depending on context and purpose of rating, rater would have more/less access to means of verification of information)
	• Does TBI use support offered by CP for purpose of transaction? Eg., Referring to a list/diary, using the organization of the conversation provided by CP (e.g. responding to closed choice questions)

Score MPC *Transaction*:	

B. Transaction Anchors		
NONE	0	**No evidence** of person with TBI **conveying content,** in order to achieve the purpose of the task.
	1	Person with TBI occasionally **conveying content**, in order to achieve the purpose of the task.
SOME	2	Person with TBI is **conveying some content,** in order to achieve the purpose of the task.
	3	Person with TBI is **conveying content most of the time,** in order to achieve the purpose of the task.
FULL	4	Person with TBI **consistently conveys content** in order to achieve the purpose of the task.

Appendix A taken from Togher et al., 2010a.

Appendix B: TBI Express

Box A: The 10-week partner training program

Session number	Title	Contents
Session 1	Introductions	Members are introduced to each other. Aims of training, group guidelines and home practice expectations are established.
Session 2	Brain Injury and communication	Educational component on TBI and communication
Session 3-4	Effective communication 1 and 2	Communication roles and rules in society. Barriers and facilitators to good communication in everyday life. General communication strategies.
Session 5	Collaboration	Techniques for communication partners to make conversations a collaborative process where both the "feel" and information exchange are more equal, shared and organised.
Session 6	Elaboration	Techniques for communication partners to organise and link conversational topics to support longer and more interesting conversations
Session 7	Asking questions	Use of appropriate and helpful questions to start and keep conversations going. Includes how to avoid negative or 'testing' questions and focus on a positive questioning style.
Sessions 8–10	Improving skill and confidence	Revision and practice of information and techniques learnt in previous sessions using the Communication Partner Communication Strategies Toolkit (figure 1). Celebration lunch for group members' achievements.

Appendix B taken from Togher, Power, McDonald, Tate & Rietdijk (2010b).

Appendix C: TBI Caregiver Survey

Introductory Agreement

Purpose

This survey is part of a research study to learn information about how paid caregivers communicate with people with traumatic brain injury (TBI).

Procedure

Participants will be asked to complete the following survey which is estimated to take approximately 10-15 minutes. After all responses have been received the information will be compiled and analyzed together. Responses will be completely anonymous and not tied to any individual in any way.

Risks and Benefits

There are no foreseeable risks or benefits associated with completing this survey. Participation is completely voluntary and can be terminated at any point during the survey with no penalty. Refusing to participate in the survey will not affect employment in any way.

Contact Information

Please feel free to contact any of the entities listed below with any questions or concerns:

- Principal Investigator: Emily Fender- fenderen@appstate.edu
- Faculty Advisor: Louise Keegan- keeganlc@appstate.edu
- Appalachian State University Institutional Review Board: irb@appstate.edu

Appalachian State University's Institutional Review Board has determined this study to be exempt from IRB oversight.

Agreement

By continuing on to the survey, you acknowledge you have read and agree to the descriptions and terms outlined in this consent form, and voluntarily agree to participate in this research, and are at least 18 years of age.

Please acknowledge the informed consent above by clicking the appropriate response below.

- ○ I understand and agree to participate
- ○ I wish to not participate

Block 1

Are you currently employed as a caregiver to one or more individuals with traumatic brain injury (TBI)?

- ○ Yes
- ○ No

Block 2

How many individuals with TBI do you currently work with?

In what settings do you provide care to the person with TBI? (please select all that apply)

- ☐ The person with TBI's personal residence (in their home)
- ☐ In the community (you accompany the person in public)
- ☐ In a group home setting
- ☐ In a day program setting
- ☐ Other (please explain)

Approximately how many years have you worked with the TBI population?

Block 3

What is your official job title?

What age range best describes you?

- 18-27
- 28-37
- 38-47
- 48-57
- 58 or older

How do you describe yourself?

- Female
- Male
- Prefer not to answer

Block 4

What is your highest level of education?

- High school diploma or GED
- Some college courses
- Associate's or 2-year degree
- Bachelor's degree
- Master's degree
- Doctoral degree
- Other (please specify)

Block 5

There is a special certification offered through the Academy of Certified Brain Injury Specialists to individuals who pass an examination and have at least 500 direct contact hours in an employment setting with individuals who have a TBI. Do you have this certification?

- Yes
- No

Have you completed any sort of training that included information about how individuals with TBI communicate or strategies that you may use in conversation with them?

- Yes (please specify the type of training; for example, was it online or in person?, what was it called?, etc.)
- No

What other kinds of training do you have? (example: First Aid/CPR; CNA)

Block 6

Do you sometimes feel frustrated when having a conversation with a person with TBI?

- Yes
- No

Block 7

Can you identify some sources of your frustration during conversations?

Block 8

Do you believe that individuals with TBI suffer socially because of impaired communication?

- Yes
- No

Can you describe some communication difficulties that individuals with TBI might experience?

What are some strategies that you use as the caregiver to help overcome communication difficulties that the person with TBI may experience?

How confident are you in your current ability to communicate effectively with individuals with TBI?

- Extremely confident
- Somewhat confident
- Slightly confident
- Slightly doubtful
- Somewhat doubtful
- Extremely doubtful

Block 9

Which of the following are commonly shared in your conversations with individuals with TBI? (please select all that apply)

- The person with TBI's personal stories or thoughts
- Your (the caregiver's) personal stories or thoughts
- Information for the person with TBI about how to complete a task
- Information for the person with TBI about a pre-planned upcoming event
- Guidance for the person with TBI to help make decisions about an upcoming event
- Guidance through a behavioral outburst of the person with TBI

Other (please add any additional topics or situations that come to mind)

Who takes more responsibility in conversations? (who starts a conversation, adds new information, asks more questions)?

- I take most of the responsibility
- I take more but not all of the responsibility
- We both assume equal responsibility
- The person with TBI takes more but not all of the responsibility
- The person with TBI takes most of the responsibility

Block 10

Would you like more training on communicating with individuals with TBI?

- Yes
- No

Block 11

What form of training would you prefer? (please rank as "1" being the form you most prefer to "3" being the least preferred)

Online Course
Workbook
In-person seminar

Other (please specify)

Block 12

Please add any additional information related to communicating with individuals with TBI you would like to share below.